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eTELEMED 2023

Forward

The Fifteenth International Conference on eHealth, Telemedicine, and Social Medicine (eTELEMED 2023), held in Venice, Italy, April 24 - 28, 2023, considered advances in techniques, services, and applications dedicated to a global approach of eHealth.

Development of wireless homecare, of special types of communications with patient data, of videoconferencing and telepresence, and the progress in image processing and date protection increased the eHealth applications and services, and extended Internet-based patient coverage areas. Social and economic aspects as well as the integration of classical systems with the telemedicine systems are still challenging issues.

eTELEMED 2023 provided a forum where researchers were able to present recent research results and new research problems and directions related to them. The topics covered aspects from classical medicine and eHealth integration, systems and communication, devices, and applications.

We take this opportunity to thank all the members of the eTELEMED 2023 Technical Program Committee as well as the numerous reviewers. The creation of such a broad and high-quality conference program would not have been possible without their involvement. We also kindly thank all the authors who dedicated much of their time and efforts to contribute to the eTELEMED 2023. We truly believe that, thanks to all these efforts, the final conference program consists of top quality contributions.

This event could also not have been a reality without the support of many individuals, organizations, and sponsors. We are grateful to the members of the eTELEMED 2023 organizing committee for their help in handling the logistics and for their work to make this professional meeting a success.

We hope that eTELEMED 2023 was a successful international forum for the exchange of ideas and results between academia and industry and for the promotion of progress in eHealth and Telemedicine research. We also hope that Venice provided a pleasant environment during the conference and everyone saved some time for exploring this beautiful city

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Patient Satisfaction with Remote Consultation at a Chronic Pain Unit

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***Abstract* — The COVID-19 pandemic represented and unprecedented global health crisis, forcing the reorganization of healthcare systems worldwide to respond to intensive care units created to treat COVID patients. Therefore, all outpatient and elective interventional procedures have been reduced or interrupted to reduce the risk of viral spread. The Centro Hospitalar de Entre o Douro e Vouga (CHEDV) Chronic Pain Unit (CPU), confronted with cancellations of all consultations and procedures, considered as non-essential or urgent, as well as the dramatic reduction in human resources, which were reallocated to essential activities, decided to start teleconsultation. Besides enabling the follow-up of patients, preventing the degradation of their clinical condition, it was intended to avoid a feeling of abandonment by the patients. This study aimed to measure patient satisfaction with teleconsultation during the Pandemic, and to understand the influence of sociodemographic variables on satisfaction, as well as to envision possible improvements in healthcare services. The results indicated a high level of patient satisfaction with the telemedicine. Despite high satisfaction most patient prefer to continue face-to-face consultation in the future. Data analysis revealed no statistically significant difference between patient satisfaction and demographic variables.**

Keywords - telemedicine; patient satisfaction; chronic pain.

I. INTRODUCTION

The first cases of infection with Sars-CoV-2, a virus from the coronavirus family, were detected in late 2019 in the Chinese city of Hubei. The zoonosis, referred as COVID-19, quickly spread around the world. In March 2020, this outbreak was declared a pandemic by the World Health Organization [1].

The COVID-19 pandemic represented and unprecedented global health crisis, forcing the reorganization of healthcare systems worldwide to respond to intensive care units created to treat COVID patients. Therefore, all outpatient and elective interventional procedures have been reduced or interrupted to reduce the risk of viral spread [2]. The shutdown of pain services in conjunction with the home lockdown has affected chronic pain management worldwide with and additional impact on patient's psychological health [3].

In Portugal, the first State of Emergency was declared between March 22 and May 2, 2020. During that period, all the non-oncological non-urgent procedures were postponed. In the CHEDV were attended hundreds of COVID-19 patients and all the anesthesiologists were reallocated to the intensive care unit, emergency services and emergency/major surgery.

The CHEDV CPU is constituted by anesthesiologists who belong to the Anesthesiology and Pain Medicine Service, with the support of other specialties such as Rehabilitation, Psychiatry, Psychology and Oncology, when appropriate. It provides healthcare to 340,000 inhabitants, a population spread over a large perimeter [10].

Until March 2020, the CPU appointments were carried out on a face-to-face basis. Confronted with cancellations of all consultations and procedures, considered as non-essential or urgent, as well as the dramatic reduction in human resources, which were reallocated to essential activities, it was decided to start teleconsultation. Besides enabling the follow-up of patients, preventing the degradation of their clinical condition, it was intended to avoid a feeling of abandonment by the patients. Therefore, during the first State of Emergency declared in Portugal, all scheduled patients of this unit were submitted to a teleconsultation by a senior physician or pain nurse.

For patients, this new consultation experience, where the interaction between the patient and clinician is performed without direct observation, may have a negative impact on the level of patient satisfaction.

Patient satisfaction can be defined as the degree of congruence between expectation and experience [4]. The quality of the service delivery experienced is defined as the gap between the expectation and the actual experience of costumers [5].

The level of patient satisfaction in the CHEDV chronic pain consultation had never been analyzed. Methodologies to assess patient satisfaction in telemedicine are unspecific, and the comparison and interpretation of results can be a problem [6]. In general, the more positive the perception of an intervention in telemedicine, the greater the likelihood of its use and benefit in clinical practice. While there have been studies examining the correlation between patient satisfaction and the implementation of telemedicine, as well

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as its impact on patient outcomes, there is a dearth of research focusing specifically on individuals with chronic pain [7, 11].

Recently, a study designed to understand the acceptance of telemedicine by chronic pain patients during the COVID-19 Pandemic in Switzerland has been published, which demonstrates the relevance of the topic [8].

The purpose of this work is to measure patient satisfaction with teleconsultation during the Pandemic, and to understand the influence of socio-demographic variables on satisfaction, as well as to perspective possible improvements in the provision of healthcare services.

This paper is structured as follows: Section II outlines the methodology used in the study, including a description of the participants, study design, and survey questions. Section III then provides a detailed account of the statistical analysis carried out on the data collected. Moving on to Section IV, the results obtained are presented and analyzed in detail. Section V delves into a discussion of these results, exploring their implications and significance. Finally, the paper concludes with an acknowledgement section and a summary of the main findings and their implications in the conclusion section.

II. METHODS

A retrospective, descriptive, cross-sectional cohort survey was conducted.

A. Participants And Study Design

The study was previously proposed and approved by the Ethics Committee of the Entre o Douro e Vouga Hospital Center.

The patients' population consisted of all the patients previously followed in the CPU that were submitted to a teleconsultation by a senior pain doctor during the first state of emergency due to Covid-19 Pandemic, declared in Portugal between March 22 and May 2, 2020.

From the universe of patients, those who fit at least one of the following exclusion criteria were not considered for the study:

- Patient deceased at the time of the questionnaire;
- Family member of a professional from CPU;
- Hospitalized patient;
- Incomplete questionnaire or misunderstandings;
- Nursing consultation;
- Patient discharged from CPU;
- Under 18 years of age.

Patients who met the criteria for inclusion in the study were contacted by telephone in order to answer the questionnaire. The telephone contact was made by a health professional other than the physician responsible for the patient. This was done to avoid possible conditioning of the response.

All selected patients gave informed consent and agreed to participate in the study. The patients who met the inclusion criteria were asked to complete a questionnaire. The questionnaire consisted of 12 simple questions, as shown in Table I. The questions were grouped by theme, each with 5 possible answers, according to a 5-point Likert scale (1 - totally disagree / 5 - totally agree):

TABLE I. QUESTIONS ASKED IN THE SURVEY

1.TECHNICAL PROBLEMS (Techn probl)
I had no technical problems in performing the consultation.
2. OBTAINING A PRESCRIPTION (Obt Presc)
I had no difficulty in obtaining a prescription.
3. UNDERSTANDING THE PRESCRIPTION (Underst Presc)
I had no trouble understanding the changes in the prescription.
4. THE IMPORTANCE OF PAIN (Pain import)
I felt that my pain was valorized by my doctor.
5. CONSULTATION DURATION (Time)
During the consultation I had the time I needed to express my symptoms.
6. SAFETY AND CONFIDENTIALITY (Safety)
During the consultation I felt my confidentiality was not threatened.
7. COMMUNICATION (Communication)
I clearly understood the explanations given to me.
8. CONFIDENCE (Confidence)
I am confident that my doctor was able to assess my symptoms during the phone consultation.
9. LACK OF PHSYCAL CONTACT (Physcontact)
I think the lack of physical contact was not a problem for the course of the consultation.
10. OVERALL ASSESSMENT OF THE CONSULTATION
I am very satisfied with the healthcare provided to me in the Chronic Pain Unit.
11. ACCEPTANCE OF TELECONSULTATION (Acceptance)
I wouldn't mind if the next appointment was by telephone.
12. FEAR OF SEVERE CORONAVIRUS INFECTION (FearCOVID)
I am afraid of becoming seriously ill due to COVID-19.

III. STATISTICAL ANALYSIS

Data analysis was performed using IBM® SPSS® Statistics Software. Continuous variables were represented with means and standard deviations. Interval data were calculated using Student test.

Spearman correlation between the listed items were calculated (Table III). A correlation of between [0.2, 0.4) was considered weak, [0.4, 0.6) moderate, [0.6-0.8) strong, and very strong between [0.8, 1].

The p-values were calculated with a chi-square test for categorical data and a t-test for continuous data. A p-value of less than 0.05 was considered statistically significant.

Missing data or unanswered survey questions were excluded from statistical analysis.

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IV. RESULTS

262 patients were submitted to a remote consultation between March 22 and May 2, 2020. From these, 47 were excluded from our study: 22 had only nursing appointment; 2 were relatives from CPU professionals; 3 refused to participate in the study; 13 don't complete or understand the questionnaire; 1 was hospitalized at the time of the survey; 3 patients died; and 3 were discharged from the CPU.

A. Sample Characteristic

215 patients met the inclusion criteria for the study. The mean participant age was 61.58 (+/-14.96). Regarding gender, the participants were mostly female (171 patients, corresponding to 79.53% of the sample). 58 of the patients have been in follow-up for less than 6 months (26.97%) and 61 for more than 5 years (28.37%).

The statistical analysis is presented in Table II.

TABLE II. DESCRIPTION OF THE SOCIO-DEMOGRAPHIC VARIABLES OF THE STUDY PARTICIPANTS

Patient Characteristics and Demographics		
Gender		
	Feminine	171 (79,53%)
	Masculine	44 (20,47%)
Age		
	Average	61,58 (+/-14,96) yrs
Marital Status		
	Married	160
	Divorced	21
	Single	18
	Widowed	16
Education		
	Illiterate	9
	Basic	106
	Secondary	91
	Higher	9
Employment Status		
	Disability pension	15
	Employed	58
	Pensioner	94
	Sick leave	24
	Unemployed	24

80.9% of the followed patients, i.e., 174 patients, were independent in the Activities of Daily Living (ADL) – Barthel Score Index. Only 5 patients (2.3%) were very dependent or totally dependent on ADL. Most patients were followed for non-oncological pain 94% (202) and predominantly from musculoskeletal causes 48.4% (104).

93% of patients totally agree/agree with the statement " I had no technical problems in performing the consultation". Also, within the dimension of technical difficulties, 86% reported no problems in obtaining the prescription, and 87.4% in understanding the changes to the prescription. In all those questions there was always patients who neither agreed nor disagreed with this statement (8.4%, 9.8% and 11.6%, respectively).

85.1% agree/strongly agree that the clinician valued their complaints during the remote consultation. A total of 7 patients totally disagreed with this statement.

Regarding the time required for the consultation, 80.5% of the patients felt that the consultation had taken an adequate duration.

Considering the current health status and compared to the previous 6 months, 40.5% (87) of patients felt no change in their condition, 35.8% (77) felt better, 18.6% (40) affirmed they felt worse, 3.7% (8) felt much better and 1.4% (3) considered themselves much worse.

After socio-demographic and descriptive statistical analysis, further statistical analysis was conducted. Regarding the question "I am very satisfied with the healthcare provided to me in the Chronic Pain Unit", it was found that 93% of the patient sample was satisfied/very satisfied with the provided services in the CPU.

Correlations were examined between the patient's overall satisfaction and other items. The results are presented in Table III.

TABLE III. CORRELATION BETWEEN PATIENT SATISFACTION WITH CPU AND OTHER ITEMS.

Patient Satisfaction	**Correlation Coef**	**p-value**
FOLLOW UP TIME (Fol time)	0.025	0.712
CURRENT HEALTH STATUS (Cur health)	0.169	0.13
TECHNICAL PROBLEMS (Tech prob)	0.285	0.00
OBTAINING A PRESCRIPTION (Obt presc)	0.258	0.00
UNDERSTANDING THE PRESCRIPTION	0,292	0.00
THE IMPORTANCE OF PAIN (Pain import)	0.481	0.00
CONSULTATION DURATION (Time)	0.475	0.00
SAFETY AND CONFIDENTIALITY (Safety)	0.276	0.00
CONFIDENCE (Confidence)	0.410	0.00
LACK OF PHISYCAL CONTACT (Physcontact)	0.446	0.07
ACCEPTANCE OF TELECONSULTATION (Acceptance)	0,476	0.08
FEAR OF SEVERE CORONAVIRUS INFECTION (FearCOVID)	0,41	0,21
AGE	0,63	0.04

There is a strong correlation between the patient age and their level of satisfaction (Cor: 0.67; p>0.05), with older

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patients found to be the most satisfied with the services provided at the CPU.

In addition to the analysis presented above, the data was used to search for correlations between other variables. A correlation was found between patient age and the difficulty in understanding the changes in the prescription (Spearman = 0.010, Pearson's R = 0.027).

We also found an association between the education level and the existence of technical difficulties in carrying out the consultation or understanding the changes in prescription (Spearman = 0.07; Pearson's R = 0.02).

A correlation was found between fear of Sars-CoV-2 infection and acceptance of future teleconsultation. It was also observed an association between patient satisfaction and confidence (Confidence), consultation duration (Time) and the lack of physical contact (Physcontact).

The statistical result suggests that there is a weak linear association between physical dependence in activities of daily living (ADL) of the patient and the impression that the lack of physical contact with the clinician by teleconsultation had on the evolution of the disease. The Pearson's Chi square test was used to examine this association, with a linear association value of 0.047.

V. DISCUSSION

The results indicated a high level of patient satisfaction with the telemedicine. 93% of the patients considered very satisfied/satisfied with the consultation by telephone.

Data analysis revealed no statistically significant difference between patient satisfaction and demographic variables: gender; age; and marital status.

The follow-up time in the unit also does not seem to influence the patients' degree of satisfaction. Only 2.3% (n: 5) of patients consider themselves very unsatisfied with teleconsultation.

86.51% had no technical difficulties in performing the consultation, obtaining the prescription (86.04%) or understanding the changes in the prescription. However, we found a statistically significant relation between the age of the patients and the existence of technical difficulties in carrying out the consultation and obtaining a prescription.

Regarding safety and privacy 86.98% (187) felt safe or totally safe during the consultation process.

Examining discrepancies in patients' perceptions and experiences with the services reveals whether the expectations of users were fulfilled, or whether they were disappointed by the care they received. Generally, expectations are shaped by prior knowledge, beliefs, and experiences. However, in telemedicine a high degree of uncertainty is associated, due to the lack of previous experience and unfamiliarity with the technology. If we add to these factors the uncertainty and fear that surrounded society due to the COVID-19 pandemic, we have exceptional characteristics, which may have altered the patients' perception in some of the dimensions of the consultation.

The population served by our unit also has relevant characteristics: is an elderly; rural; poor; and highly dependent on others for access to health services. The distance between home and hospital can be more than 50 km. Thus, accessibility can become a problem.

On the other hand, we detected a high fear of Sars-Cov-2 infection in this age group, which may have conditioned the results of the satisfaction survey. A question arises: Where patients satisfied with teleconsultation or with the fact that they had less risk of infection by not travelling to the health services?

During the first phase of the COVID-19 pandemic in Portugal, all non-essential services were closed. Thus, most chronically ill patients were left without a follow-up, which may have led to a feeling of abandonment, with possible worsening of physical and psychological symptoms.

The fact that a senior chronic pain physician, although not the attending physician, met the connected patient and worried about his/her health condition, may have conditioned the patient's satisfaction with the consultation. This analysis, although not part of the objectives of this work, may affect the results. This can be deduced from the interpretation of the answer to the question on maintaining teleconsultation in the future: only 29% prefer this scenario. The percentage of patients who do not know how to answer (17%) stands out, belonging to the global uncertainty scenario. A question regarding the "maintenance of teleconsultation in a non-pandemic scenario" would have been pertinent, although not asked in this study.

In terms of future perspective, we can consider the role that teleconsultation will have in the daily practice and if it can be a valid alternative to traditional consultation. Although this was not the object of this study, it is undeniable that it should be considered as an option, depending on the circumstances, both medical (type of consultation) and patient (in elderly patients, with travel difficulties, with stabilized pathology). The use of new digital tools in favor of medicine is important. Thus, according to the patient's possibilities and the hospital's availability, the introduction of video calls, or the use of mobile applications, may improve the quality of the consultation and the outcome of treatments.

Nevertheless, our study is conditioned by the circumstances of the COVID-19 pandemic, so this should be the subject of new studies, rather than the conclusion of the present work.

VI. CONCLUSION

The main purpose in assessing patient satisfaction and experience is to try to understand how the patient was treated, what their perception of the quality of care was, and to identify areas for improvement to achieve better outcomes.

The primary outcome measure of this retrospective, descriptive, cross-sectional cohort survey, is to determine the level of satisfaction of the patients submitted to a phone consultation during the first state of emergency in Portugal, due to COVID-19 pandemic. Based on the results, we conclude that the vast majority are satisfied/very satisfied.

Data analysis revealed no statistically significant difference between patient satisfaction and demographic

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variables (gender, age, marital status). Most patients reported no difficulties in obtaining an appointment, obtaining a prescription, or understanding changes to prescriptions. However, we found a statistically significant relation between the age of the patients and the existence of technical difficulties in carrying out the consultation and obtaining a prescription.

Prospecting future improvements, we also pretend to evaluate telemedicine as an alternative to traditional in-person follow up in a Chronic Pain Unit. In this scenario, 68.4% of our sample prefer teleconsultation instead of traditional consult.

Is telemedicine a reliable alternative to traditional physical consultation in a Chronic Pain Unit in Portugal? It can certainly play a significant role, although always adapted to the needs of the population it serves. Data on patients who preferred to continue with the traditional consultation was not analyzed and should be the subject of further research, developed in a post-pandemic context.

How the fear for COVID-19 affected patients' satisfaction with teleconsultation is a question that could be asked. Although the answer was not the subject of this study, we can conjecture that the impact may have been significant. Whether by maintaining contact with the health services at a time of general confinement in which feelings of abandonment and isolation were frequent, or by avoiding visits to hospital, reducing the risk of viral transmission, it is possible that patient satisfaction with teleconsultation has been overestimated.

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A Population-based Study from Electronic Health Records on the Comorbidities of Dementia Older Adults in Hong Kong

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***Abstract*—Dementia is a condition characterized by a group of symptoms that affect memory, learning, and cognitive function. It negatively impacts patients' daily functional skills and independence, particularly in the later stages of the disease when comorbidities are often present. With the global aging problem leading to an increasing number of dementia cases, there is a significant burden on healthcare systems worldwide. Despite growing research on risk mitigation, early diagnosis, and intervention of dementia, few studies have focused on the developmental trajectory of the disease. In this study, we utilized the Hospital Authority (HA) Electronic Clinical Record to analyze structured clinical data of dementia patients in Hong Kong. Using mixed methods, we created a population-based case-control cohort to determine the association between dementia and other disease diagnoses based on ICD-10 codes. We identified significant associations with comorbidities in the categories of "Endocrine, nutritional and metabolic diseases" and "Mental, Behavioral and Neurodevelopmental disorders". Further, we plan to employ machine learning models to predict patient comorbidities data and understand the complex short-term and long-term dependencies in dementia progression.**

Keywords-dementia; comorbidities;clinical data;machine learning.

I. INTRODUCTION

Dementia includes a group of symptoms affecting memory, learning, and at least one other cognitive domain (such as aphasia, apraxia, agnosia, or executive function), which may be part and all impaired in different stages of the disease. Dementia negatively affects the patient's daily functional skills and independence, especially when they enter the later stages with comorbidities. Therefore, the increasing number of dementia with the worldwide ageing problem results in a significant burden for general health care in many countries, especially since several comorbidities are usually with dementia. There is growing research focus on risk mitigation, early diagnosis and intervention of dementia, but few have been conducted to determine the developmental trajectory of dementia (For review, please see [1]).

II. MOTIVATION

To better understand the comorbidity of dementia in the Hong Kong ageing population, a population-based study was conducted to analyze the structured clinical data of dementia patients using the real world clinical data. Our objective is to determine whether we can discover the higher risk of comorbidity of dementia through their dementia journey, since the patients were diagnosed with dementia. To achieve this, we utilized the Hospital Authority (HA) Electronic Clinical Record with a sample of 200,000 patients' digital files in the years of 2007 to 2017.

III. METHODOLOGY AND INTERIM RESULTS

The current study used mixed method to conduct the data analysis. First, our objective in this stage was to determine which disease diagnosis (in the format of structured ICD-10 codes) had a significance association with the diagnosis of dementia. We created a population-based case-control cohort of patients based on the presence (cases) and absence of dementia (controls) during this period in the database. We then filtered the data with the diagnosis of dementia in any year using The International Classification of Diseases, Tenth Version (ICD-10) codes (F00-F03). The related clinical data can be extracted, including their comorbidities throughout their disease journey. As in the control group, a set of random samples of individuals was matched by those based on the age of diagnosis of dementia and gender with a 1:1 ratio. The dependent variables are the comorbidity in the format of ICD-10 coding. By going through the categories of A to Z in ICD-10, we identified the essential dependent variables (i.e. comorbidity) that had a significant association with dementia. The significant association is tested using Chi-Square Test. We found that significant associations exist in "Endocrine, nutritional and metabolic diseases (Category E)" and "Mental, Behavioral and Neurodevelopmental disorders (category F)" in the Hong Kong population.

After the major categories of comorbidity with significant association with dementia have been identified at the first stage, we will further employ machine learning models to learn the development of comorbidity after the diagnosis of dementia. In this part, we will build and validate predictive machine learning models to predict patient comorbidities data (Fig 1). We will primarily focus on the multivariate and temporal nature of patient comorbidities data. Using this data-driven method [2], which can build relationships underlying all the available factors, we aim to create inherent relationships at multiple levels and scales, including 1) the short-term scale recording, indicating the correlations between consecutive medical records during one clinical episode within a short timeframe (e.g., a few days) and clinical events such as necessary lab tests involving a

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wide range of vital sign measurements or medical notes indicating the progression over a short period of time; and 2) the long-term dependence, which usually happens among different clinical episodes and indicates the trend in patients' progression of comorbidities. Such trends also rely on the summary of each clinical episode. The integration of short and long-term dependence on clinical data is required to provide more precise predictions. For example, the trend of a patient's vital signs during the previous 24 hours on the prognosis, some of the comorbidities (e.g., diabetes, cardiovascular disease, stroke, hip fracture, etc.) and the demographic data (e.g., older age, male gender, or lower socioeconomic position) may indicate a higher probability of mortality [3]. In this view, a predictive model should follow and capture the complex short-term changes of clinical events and their influences over time (i.e., long-term dependencies) to understand the context of dementia progression (e.g., a hip fracture incident and its recovery influence on the dementia progression).

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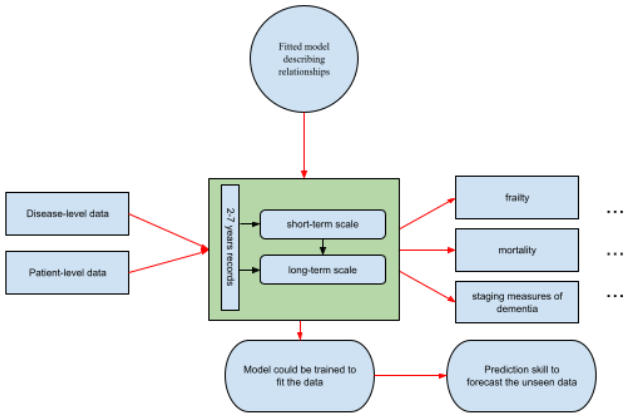

Figure 1. Input and Output of the Machine Learning Model

Designing Nudges in eHealth

Short paper/work in progress

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***Abstract*—Digital nudging are much used in eHealth and public health promotion. Such nudges can be very useful for patients and citizens in general, as it may help them self-manage their own health, and may in many cases even save lives. But the designing of digital nudges is critical, for the purpose of the nudge to be achieved, and negative consequences of the measure avoided. This study disseminates the state of art in the field and will then seek to elicit purposeful design principles by combining Design Thinking and participatory design with frameworks for compliance with general health policies. The results so far show that this avenue for research seems promising**.

Keywords-digital nudges; Design Thinking; Jobs to be done; user journey funnels; health promotion.

I. INTRODUCTION

Nudging is a "choice architecture", which involves all the outside forces that may subtly guide one's decisions in one direction or another and provide an effective and viable public health strategy [1]. Digital nudging is the use of user-interface design elements for guiding people's behavior in digital choice environments [2]. According to Schneider et al [3] the interactions of designing digital nudges consists of the four phases Define the goal, Understand the user, Design the nudge, and test the nudge (Figure 1). Depending on the outcome of the Test-phase, the three previous phases are iterated again.

Nudging initiatives in a public health setting typically involve arranging environments in ways that make health-promoting behaviors more likely. A classic, oft-cited example of nudging involves positioning healthy food types more prominently than unhealthy ones in cafeterias [1]. Nudging relies mainly on System 1 reasoning, which is quick, intuitive, and automatic, as opposed to System 2, which is slower and more deliberative [4]. Although many nudging techniques are shown to have the intended effects, it is unclear whether they would work outside the study setting [5].

Nudge Theory presents a new collection of methods, deemed "nudges", which have the potential for low-cost and broad application to guide healthier lifestyle choices without the need for restrictive regulation [6]. Nevertheless, there has not yet been a large-scale examination of the effectiveness of nudges, despite several policy making bodies now considering their use.

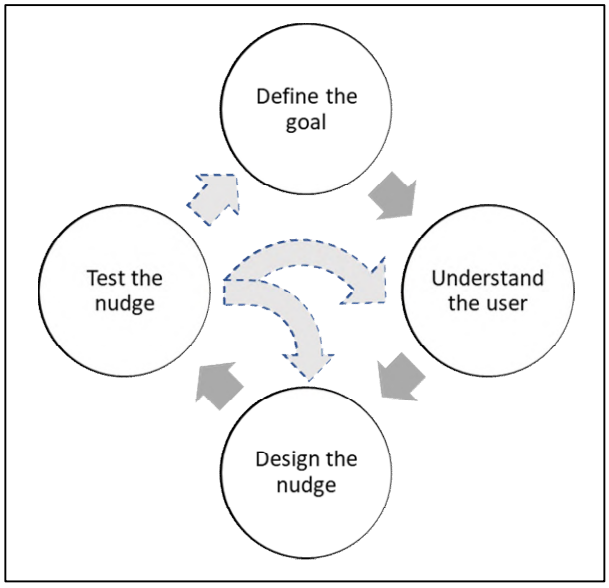

Figure 1. Digital nudge design iterations.

Nudging has been imported into the public health context to address the intransigent problem, from a political-administrative point of view, of individuals not doing what is most beneficial for themselves health-wise [7]. A few articles documented that nudging seems to offer public

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health a number of advantages: 1) information based public health campaigns are ineffective in producing desired health changes; 2) nudging operates directly on behaviors rather than attitudes and knowledge (behaviors has been described as the main concern of health promotion); 3) unlike legislating for better public health, nudging interventions preserve individuals' autonomy [5]. Scoping reviews by Ledderer et al shows that most lifestyle-related "nudging" interventions and mechanisms are related to dietary choices [5]. Limitations are big regarding study design, target groups, duration of the intervention, and measures of effectiveness. Critical discussions about nudging are required, and there needs to be ongoing exploration of whether nudging interventions are gaining foothold in various arenas.

As a good example, it was found that nudges resulted in an average 15.3 % increase in healthier dietary or nutritional choices, as measured by a change in frequency of healthy choices or a change in overall caloric consumption (a good public health strategy to combat obesity) [6].

This short paper represents a work in progress. The goal is to elicit design principles for good, effective, and ethically sustainable digital nudges. The work so far, reported here, represents a preliminary literature review for mapping the state of art in this concern, and comparison with methodologies from innovation management. The problem statement here is whether Design Thinking related methods may inform Nudge Theory and health promotion.

II. LITERATURE REVIEW

A preliminary literature review has been performed using the following method and criteria. The search was done in Scopus electronic database [8] that partially includes databases MEDLIE and EMBASE ++. The search criteria (search string) are shown in Figure 2.

TITLE ((digital* OR online OR web*) AND nudg*) AND TITLE-ABS-KEY (health* OR promot* OR wellbeing OR "well being" OR "physical activ*" OR sedentar* OR diet* OR nutrition* OR food OR lifestyle* OR "life style*")

Figure 2. Search string

Using this string, February 2023, we found 44 articles. The references of the found articles can be found on the web address, Learning Service-Organization [9]. Of 44 articles, 13 are outside scope (dealing with eco friendliness only), or not concluded studies. Of the remaining 31 articles most are concerned with healthy eating. Some articles are concerned with increasing digital literacy among users, responsible use of internet and social media, for more cost-effective public health measures, or more effective healthcare through adoption of technology. A recurring theme is that nudges need to be simple to be effective and strike the right balance of measures. Too much pressure may be counter productive. A general impression of the found articles is that they as a rule seems to be sympathetic and un-critical to the use of digital nudging in general.

Here follows some examples of themes (in this article's authors interpretation), found in the reviewed articles:

a) Nudging indirectly, encouraging development of the factors leading to more responsible behaviour; (here:) involvement in children's nutrition

b) Online grocery shopping: Two-step nudges may be needed, to advocate both eco-friendly and nutritional quality food. Default shopping carts increase nutritional quality.

c) Covid-19 contagion awareness: Nudges can be tailored by designers to different users.

d) Renewal of subscription (disability parking), nudging towards using digital channels. A simple letter appealing using the argument of cost saving, had effects.

e) Nudging general compliance with rules for behaving well, using China's social credits system as a case, shows that freedom to opt in or out, reduce the feeling of intrusiveness.

f) Does the goal justify the means? A survey tests attitudes towards nudges. Freedom for users, transparency and the urgency of goals are important factors found.

g) Switching meat-eating to plant-based: health arguments are the most effective.

h) Health app design may benefit from behavioural economics.

i) Nudges may promote taking part in population-based screening programmes, such as mammography.

j) Study provides insights especially for digital physical activity breaks for students during home studying.

k) Coping is better that threat in an appealing for secure online behaviour.

l) Healthier lifestyle: Finding right amount of nudging measures is critical. Too much information may cancel out effects.

m) Social media and privacy issues regarding minors.

n) Digital healthcare: For a digital nudge to work, it needs to address a user's automatic thoughts; appear when a user is open to making a choice; provide discrete, easy steps toward a goal; and offer positive reinforcement.

III. LESSONS FROM DESIGN THINKING

As a designer of digital nudges, one must strike the right balance of measures. This issue is arguably like the ones facing developers of good designs in general. Design thinking-inspired service design has emerged, especially the last ten years, as a popular methodology. Especially, the data- and telecommunication industry has embraced the concept.

Design Thinking iterations are depicted in many ways. Figure 3 shows one of the more common ways [13]: Empathize with users (a parallel to understanding the user, ref. Figure 1.), Define the problem space, Ideate solutions, Prototype solutions, and Test solutions. The similarities with

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the Digital nudge iterations as depicted in Figure 1 are striking, so arguably, the methods are interchangeable.

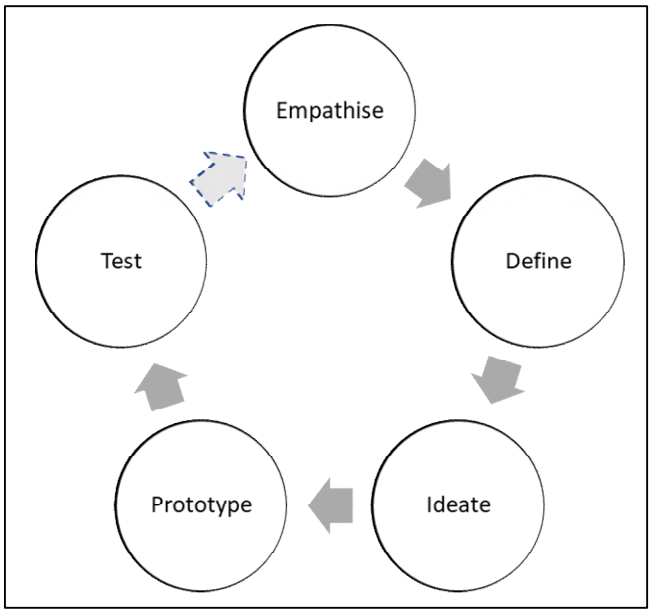

Figure 3. Design Thinking, iterations.

A method often associated with Design Thinking and the phases of Empathizing with users and defining their needs and goals is Jobs to be done – theory [10][11]. The theory in short states that the consumers (citizens, customers, users, or patients) "employ" concepts (solutions, products, or services from a variety of different categories) to cover their needs and long term-goals, see Figure 4. The consumer or citizens experience with the concepts they employ in the now situation (AS-IS), may vary. They may experience both benefits and hurdles in the present situations. In mapping these hurdles, a designer may find clues as to why a nudge does not perform well.

Jobs can be direct (cover core needs), related, emotional, product life cycle based, economic decision based etc. Citizen needs are stable and consistent over time (changes slowly). They are even similar between citizens in the same situation and context, so that if one manages to map these needs, by empathizing with the target group, even with a small number of informants, one should be able to see patterns. Citizens choose concepts (products and services) from a variety of sources. So, digital nudging can be seen as an instrument to direct those choices, a choice architecture.

The adoption of such Design Thinking techniques potentially opens for using other similar tools in nudge design, like creating personas (a narrative and visualization of a typical member of a target group), and story boarding, visualizing the user journey in a patient history [13].

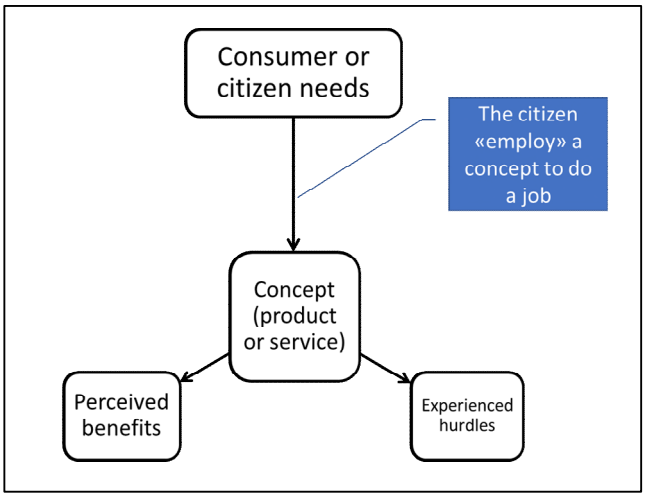

Figure 4. Jobs to be done Theory, AS-IS situation.

The user's process of "employing" a solution is a complicated process with many steps. Digital nudge designers may perhaps benefit from acknowledging this and limit the scope of the nudge, to nudging one stee at the time. The user journey or conversion model is often drawn like a funnel, since not all citizens are converted from one step to the other. This version, Figure 5, is inspired by Rogers [12]. It consists of the steps Situation awareness, users being able to assess hers or his own condition, Attention (to potential solutions), Interest, Desire, and Action ("employing", acquire the solution). The step Loyalty symbolizes the users staying with the solution, e g health promotion program, compliance. The two last steps "Advocate" and Peer mentors, symbolize the user take a passive or even active role in promoting the program towards other new users.

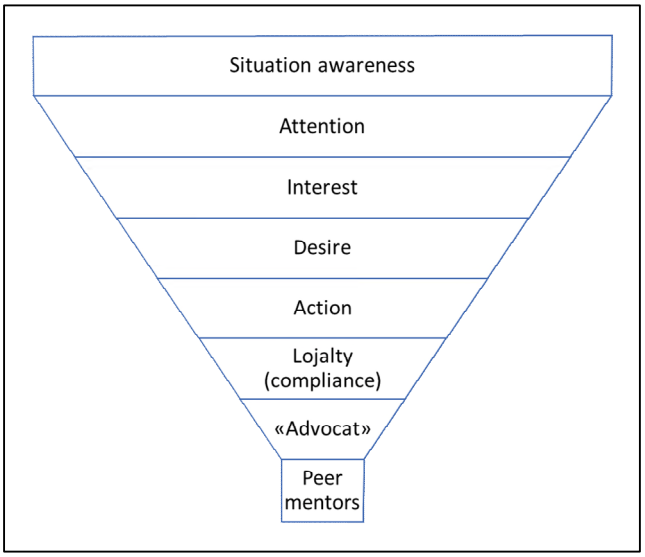

Figure 5. User journey- or conversion funnel.

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IV. PRELIMINARY RESULTS

We propose that designers of digital nudges in eHealth may benefit from the study of methods associated with Design Thinking, Jobs to be done theory and user journey design.

The citizen must be perceived as an agent that combines information from several sources and is a part of a network of users that share their points of view [12]. An understanding the process of conversions and Jobs to be done, as seen from the users, together with the literature on public health nudges [5] and others, may inform better and more sustainable digital nudges in future.

Jobs to be done theory in combination with mapping the user journey may provide data for constructing efficient tests, checking the conversions step for step, identifying where along the journey the users are lost, and pinpointing areas for improvement in a health promoting program, in a future TO-BE situation (Figure 6).

This article is a work in progress and contains untested propositions. More work is needed to substantiate the claims that are put forward here.

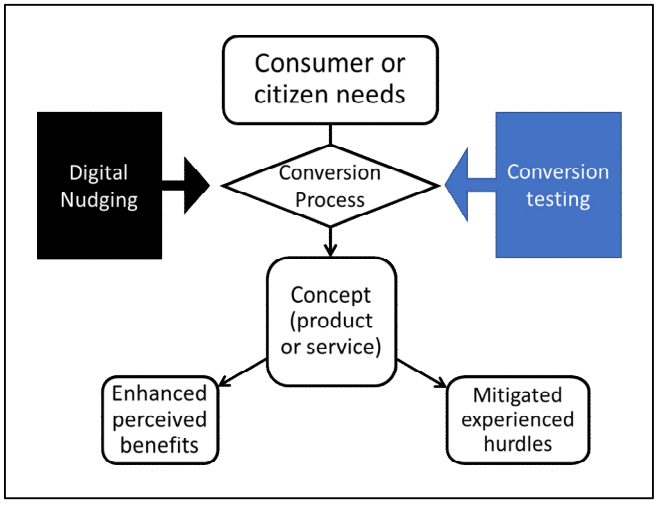

Figure 6. Jobs to be done TO-BE situation, combined with nudging.

There are more themes of interest to the scope of our article, to be found. Since this is a work in progress, this article's authors will extend the literature search using forwards searches and fewer search criteria in future. We will also scrutinize central finds closer in later articles in this area of concern.

V. CONCLUSION AND FUTURE WORK

This study has come some way in disseminating the state of art in the field of interest. We have shown similarities and analogies between digital nudges design and Design Thinking. These similarities lead us to the proposition that Design Thinking methods may inform the design of successful digital nudges in public safety, health, and healthcare.

Future work may consist of an extended search in literature as well as work with a model for an architecture framework or -platform, and an architecture development process, perhaps leveraging the aid of artificial intelligence for analysis and design.

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Legal Preparedness for Incorporating Telemedicine into the Post Pandemic Health Care Ecosystem: Taiwan Experience

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***Abstract*—While the COVID pandemic is coming to an end, will the telemedicine surged during the pandemic fade away or become a "new normal"? This paper reviews the application of Taiwan's digital technology in the pandemic, discusses the suitable scenarios for telemedicine, and introduces the responding legal/regulatory amendments. The authors argue that telemedicine has a potential to solve the care scarcity problem in an aging society, and the law should be more proactive in regulating telemedicine from a wider perspective aiming to better facilitating decentralization, resource-integration, and precision care.**

Keywords-legal preparedness; Taiwan; Telemedicine; Telehealth; COVID; pandemic.

I. INTRODUCTION

Taiwan's National Health Insurance (NHI) system is known for its high quality and low cost. In 2019, NHI provided 23 million residents with comprehensive medical services at a rate of 6.54% of GDP. A significant portion of this success can be attributed to the effective use of information technology. Since 2004, the NHI IC card has been in use, which integrates the cardholder's basic information, insurance information, medical information, and health administrative information. During the COVID pandemic, a simple card swipe can determine a cardholder's travel history and implement necessary quarantine measures. In 2014, NHI further introduced the "NHI MediCloud" system, which integrates patients' medical records from different hospitals on a single platform, allowing medical professionals to better understand the patient's medical history. When a COVID-positive patient needs to use Paxlovid, an oral medication, also known as nirmatrelvir/ritonavir, used to treat COVID-19, Taiwan's doctors can use this system to check for potential drug interactions. In addition, through digital contact tracing, electronic fencing, and digital monitoring of individual or population mobility flows, Taiwan was able to keep its number of confirmed COVID cases to only 800 by the end of 2020, when the global total exceeded 83 million.

While the COVID pandemic is coming to an end, will the telemedicine surged during the pandemic fade away or become a "new normal"? In Section II of this paper, we will discuss the legal restrictions in Taiwan regarding telemedicine, as well as how the COVID-19 pandemic has led to greater openness towards it. Section III will outline the various legal adjustments made in Taiwan as a result, including the Telemedicine Rule, Regulations of Making and Management on Electronic Medical Records in Medical Care Institution, Medical Device Act, and Pharmacists Act. Finally, in Section IV, we will provide a summary of the impact of telemedicine on healthcare in times of care scarcity.

II. OMICRON AND TELEMEDICINE

Article 11 of Taiwan's Physicians' Act stipulates that doctors must treat patients "in person", with a limited exception of remote and isolated areas or some special situation. That is, telemedicine is not allowed. However, in April 2022, the Omicron outbreak occurred in Taiwan, and given that vaccination in Taiwan has become quite widespread, the government adjusted the definition of COVID cases: anyone having a positive rapid screening result confirmed by medical staff would be immediately considered a confirmed case. This made it necessary for the medical system to respond to the outbreak through telemedicine, and during the period from May 15 to June 22, 2022, alone, the number of patients using telemedicine reached 1.85 million [1].

III. LEGAL/REGULATION AMENDMENTS IN TAIWAN

Telemedicine is a form of healthcare that involves real-time audio-video communication, as well as real-time audio and telephone communications. While the process may seem simple, it requires significant coordination, such as allowing for the reading and writing of medical records and the use of medical devices or equipment. Additionally, it is important to ensure information security and privacy throughout the process. After the telemedicine consultation, measures such as drug delivery and health insurance coverage must also be taken into consideration. To facilitate telemedicine during the pandemic, the Taiwanese authority issued necessary regulation amendments.

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A. *Rule of Medical Diagnosis and Treatment by Telecommunications (the Telemedicine Rule)*

The Telemedicine Rule defines in detail the scope and situations of “remote areas” and “special circumstances and urgent situations”. When the criteria above are met, doctors may use telecommunications methods to inquire about illness, set diagnosis and issue prescriptions, and treatment may be dispensed by nursing or obstetrics personnel belonging to health organizations. The term "special circumstances" refers to (1) patients who require close monitoring within three months of acute hospitalization, (2) residents of long-term care facilities, (3) integrated care recipients of family doctors, (4) recipients of home health care integrated plans, and (5) international patients. As for "urgent situations," it refers to situations where immediate medical treatment is required to save a life or to address an emergency [2].

In February 2020, Taiwan's health authorities clarified through an explanatory letter that patients who require immediate medical treatment or who need to see a doctor during home isolation or quarantine are considered to be in urgent situations. Chronic disease patients who are stable are considered to be in special circumstances [3][4]. Then in May 2021, the door to telemedicine was further opened, as long as the medical institution has been designated by the local health authorities, it can treat outpatients via telemedicine [5][6].

Currently, Taiwan is preparing to revise the Telemedicine Rule. In the draft, in addition to maintaining the existing framework, it is also planned to add the following five situations as special circumstances in which telemedicine can be used: long-term medication care for chronic diseases, end-of-life care, care for mobility-impaired patients, care for disasters, infectious diseases or other major changes, and other situations designated by the competent authorities [7]. From this, we can see that although telemedicine may be considered an exception to face-to-face medical treatment, these special types are all intended to increase the accessibility of medical care for those who have difficulty using general medical care.

B. *Regulations of Making and Management on Electronic Medical Records in Medical Care Institutions*

A key element of telemedicine is communication networks and other information and communication technologies or equipment. Studies have shown that the highest proportion of video software used for telemedicine consultations during the epidemic in Taiwan is Line (54%), followed by Zoom (39%) [8], and whether these software have sufficient protection for security and privacy is in question.

In July 2022, Taiwan announced a new version of the Regulations of Making and Management on Electronic Medical Records in Medical Care Institutions. In response to information and communication security, it added the use of encryption mechanisms that comply with international standards and also made relevant regulations for the electronic medical record exchange format to increase interoperability. These all help to improve the protection of information and communication security [9]. In addition, Article 18, Paragraph 2 of the draft of Telemedicine Rule also added a provision regarding "the information system used for telemedicine, involving the transmission, exchange, storage or issuance of prescription, examination, or test results, shall have personal identity verification and comply with the international standard organization's common data transmission encryption mechanism, and shall comply with the relevant regulations of the electronic medical record production and management regulations for medical institutions" [7]. Although there are no clear regulations for the equipment or software used in telemedicine, there is further protection for the storage and upload of medical record-related information.

C. *Medical Devices Act*

In the process of telemedicine, in addition to the software used for video, many medical equipment and even AI can assist patients in obtaining physiological data or tracking and monitoring diseases. For medical device hardware, there are already laws and regulations for medical devices to ensure safety and quality, however, for software, due to the characteristics is different from hardware [10], and for AI-based deep/machine learning products, the same regulatory approach may not be appropriate [11]. How to regulate software is challenging many countries. Taiwan implemented the Medical Devices Act on May 1, 2021, in which the design of medical device software is included as part of the manufacturers' responsibilities to be managed [12]. Additionally, guidelines for medical device software and AI products have been released to provide a basis for compliance within the existing legal framework.

D. *Pharmacists Act*

Many telemedicine services require a prescription from a doctor. In the past, telemedicine in Taiwan also followed this principle. However, although Taiwan has implemented a separation of prescribing and dispensing of drugs, in practice, most medical institutions have attached pharmacies and drug revenue is also a source of hospital income[13][14], so the proportion of prescriptions issued is not high. In the past, patients usually had to go to the hospital to pick up their medication after telemedicine consultation, but this became inconvenient during the pandemic. Therefore, the Ministry of Health and Welfare, citing a meeting record from November 30, 2017, stated that pharmacists can personally deliver medication to homes, but only within the county or city where they are registered to practice, which is compliance with the Pharmacists Act [15].

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The Taiwan Association of Young Pharmacists also advocated for the use of electronic prescriptions as a support for telemedicine during the pandemic to reduce the risk of infection. In response to this call, the draft Telemedicine Rule have also included provisions for electronic prescriptions [16].

As for the types of medications that can be prescribed, there were no restrictions in the past, but the new draft regulations have added a provision that generally prohibits the prescription of controlled drugs, similar to many states in the US.

IV. TELEMEDICINE AND CARE SCARCITY: CLOSING REMARKS

The problem of aging and low birth rate in Taiwan is quite serious. In 2021, the population over 65 years old accounted for 14%, while the number of newborns was only around 150,000, setting the world record of low birth rate. The problem of care scarcity is imminent, and many elderly people living alone in cities can benefit from telemedicine. Taiwan's laws are clearly aware of this problem, so they are deliberately turning telemedicine from an exception to a new normal. Although there are still many challenges to overcome, increasing the scope of telemedicine and enhancing the requirements for information and communication security, as well as setting up new electronic prescriptions, can make telemedicine both convenient and safe. Additionally, through regulations on AI, medical software, etc., manufacturers have the opportunity to better understand the regulatory framework, so that future telemedicine can provide more comprehensive care. And with the coverage of the National Health Insurance, telemedicine can not only ensure the medical accessibility of the people, but also make it affordable.

Even as the pandemic comes to an end, the widespread use of telemedicine is expected to change the medical system. Currently, telemedicine in Taiwan is still mainly based on synchronous telemedicine as defined by the AMA. However, in the era of digital health, our research team has also proposed the concept of the digital health era: the DIP model, which shifts healthcare services from large hospitals to home care ("Decentralization"); by "Integrating" health information collected by different sources, we hope to provide more "Precision" care for the public. This approach may also require the use of asynchronous telemedicine to achieve. Currently, the NHI Administration in Taiwan is also actively using existing databases to assist the development of AI and precision medicine in the biomedicine industry, while ensuring individual privacy, with the goal of improving the quality of healthcare services in the future [17].

The development of telemedicine has brought numerous benefits to healthcare, but it also requires infrastructure development and policy considerations to ensure that resources are allocated to the most in-need populations and that information security and privacy are safeguarded. Additionally, the development of medical device software and AI cannot be overlooked, and product safety, efficacy, and reliability must rely on proper regulatory design. In particular, as AI is advancing rapidly, ethical issues must also be further addressed. Therefore, as technology develops, policies and laws should also continue to be updated and discussed in order to respond to changing needs.

ACKNOWLEDGMENT

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We would also like to extend our sincerest thanks to Professor Tsuen-Chiuan Tsai for her exceptional leadership and guidance throughout this project. Her unwavering commitment and dedication to this research have been a constant source of inspiration, and her contributions to this study have been invaluable.

Finally, we would like to acknowledge the hard work and efforts of all team members involved in this project. Their support and collaboration have been essential to the success of this research, and we are grateful to have had the opportunity to work with such talented individuals.

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Innovative Framework for Secure Healthcare Data Management: Utilizing Ethereum Blockchain

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***Abstract*— In this paper, we propose an enhanced framework based on Ethereum blockchain technology for the healthcare sector. Currently, healthcare systems are often centralized, with a single entity controlling and managing patient data. This can make it difficult for patients to access and share their medical information, while also creating potential security risks. Furthermore, existing frameworks may not be able to manage large amounts of data due to Ethereum's scalability limitations. An Ethereum-based framework utilizing blockchain technology could help address these issues by providing a decentralized and secure system, giving patients greater control over their data and reducing the risk of unauthorized access. Additionally, Ethereum-based smart contracts could automate various healthcare processes, such as claims processing and appointment scheduling, improving efficiency and reducing administrative costs. This paper contributes to the development of such a framework by utilizing Apache Kafka techniques to build a private Ethereum blockchain that improves scalability and generates immutable and secure records via smart contract-generated hashes as it is immutable, secure and scalable.**

Keywords—Decentralized AI; Blockchain; Ethereum; Healthcare

I. INTRODUCTION

By enhancing the security and interoperability of electronic medical records (EMRs) [1] and opening up new use cases like clinical trial data sharing and precision medicine, blockchain technology has the potential to completely transform the healthcare sector.

The ability to create a safe, decentralized record-keeping system is one of the key advantages of adopting blockchain in healthcare. EMRs can be stored on a blockchain, enabling healthcare providers to access and update them in real time while maintaining a tamper-proof record of all changes. This can help to reduce errors and improve the accuracy of medical records [2].

Another potential use case for blockchain in healthcare is the sharing of clinical trial data. By using a decentralized platform, researchers can securely share data with one another and with regulatory agencies, helping to accelerate the development of new treatments and therapies.

Precision medicine is another area where blockchain could have a significant impact. By using blockchain-based platforms, healthcare providers can securely share and access genomic data, enabling them to tailor treatments to the specific needs of individual patients.

Overall, the use of blockchain in healthcare [3][4] has the potential to improve the security, efficiency, and interoperability of the industry, leading to better outcomes for patients.

Transparency and communication between patients and healthcare providers have improved as a result of the usage of blockchain technology in the healthcare sector. Because of duplications, the use of various names and identities, and their availability across many networks, healthcare records are becoming larger and more complicated, but they have not yet been optimised for these characteristics. Additionally, it is now crucial to maintain data security and stop illicit activity. Patient data can be utilised or sold if unauthorised people are permitted access, and everyone with access will be able to see the personal information of the patients. Data privacy for patients is essential for effective healthcare administration[1].

We are proposing that every time doctors meet a patient, information on underlying illnesses, food or drug sensitivities, and prescribed drugs must be gathered. In order to effectively diagnose and treat patients, these data allow for the reduction of needless laboratory or imaging procedures. Physicians can access medical information about patients who often attend an emergency department (ED) [5] without the need for an extra report.

In Malaysia, medical records are still commonly transmitted through paper or telephone when patients elect to shift from one hospital to another. This is often referred to as the "discharge summary" process, where the patient's medical records are printed out and given to the patient to be carried to the next hospital, or are sent through fax or email. However, the adoption of digital medical records in Malaysia still faces challenges, such as limited funding and technical infrastructure, as well as concerns around data privacy and security. It is important for healthcare providers and policymakers to continue to work towards a more seamless and secure system for sharing medical records, while also addressing these challenges and ensuring the privacy and security of patient data. In contrast, it can be challenging to learn a patient's whole medical history when they unexpectedly visit a neighboring hospital, particularly in an emergency, as patients sometimes forget specifics about their former illnesses, dosages, or drug usage. Personal health records (PHRs) connected to hospitals can offer reliable data, but if the hospital does not create and distribute PHRs, the information is not accessible electronically [6].

The paper is organized into several sections, each with a specific focus. In Section 2, the authors address objections that may arise regarding the proposed health record management platform. Section 3 provides background information, including a discussion of Blockchain in Healthcare and a review of prior system architectures. This section helps to contextualize the proposed platform and its potential benefits. Section 4 is dedicated to the proposed platform itself, which is blockchain-based and utilizes Kafka, smart contract hash architecture. This section provides a

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detailed overview of the platform's architecture and features. Section 5 covers the performance metrics, providing a quantitative analysis of the platform's capabilities. In Section 6, the authors offer a discussion of the platform, including its strengths and weaknesses, and consider how it could be improved in the future. Section 7 presents the conclusions that can be drawn from the proposed platform and its potential impact on the healthcare industry. Finally, the authors include Acknowledgments and References sections. The organization of the paper helps to provide a clear and concise understanding of the proposed health record management platform and its potential benefits for the healthcare industry.

II. OBJECTIVES

In the envisaged architecture, the blockchain regulates the authorization of data transfers between patients, healthcare providers, and other users. The blockchain uses Apache Kafka to scale the incoming data and manage it in immutable logs. The blockchain does not physically replace the electronic health record system since the majority of hospital information systems store comprehensive Personal Health Records (PHRs) in a secure database on site or in a backup location outside the hospital. Only the data's security, confidentiality, integrity, and availability [3] are ensured by the blockchain's design. Stakeholders have access to read and write electronic health record data that can be securely sent to and from other systems via the blockchain.

The main contributions of this paper are:

- To present the proposed framework for the health information records on Ethereum blockchain.
- To present comprehensive literature for readers relating Blockchain in Healthcare and on security and privacy of the Electronic Health Record (EHR) and Personal Health Records (PHR).
- To provide an understanding of the state-of-the-art techniques implemented in the healthcare and blockchain
- To get cryptographic security visa Hash code in smart contracts which are only accessible to the designated personnel.
- This architecture is formed via a private P2P network, where health records are organized into data blocks comprising a linked list and a distributed ledger of health data.
- This architecture introduced the blockchain scalability issue with the data management can be an issue. The proposed framework not only address the security as well as scalability of data while using blockchain.

III. BACKGROUND

Blockchain technology is based on cryptography, which is used to secure transactions and ensure the privacy of users. Two key cryptographic concepts used in blockchain are hashing and smart contracts [4][16][17].

Hashing is the process of taking an input (or "message") and returning a fixed-size string of characters, which is called the "hash." The same input will always produce the same hash, but even a small change to the input will produce a very different hash. This makes it useful for verifying the integrity of data, as any changes to the input will result in a different hash [8].

Smart contracts are self-executing contracts with the terms of the agreement written directly into code. They allow for the automation of certain processes, such as the transfer of assets. They are stored and replicated on the blockchain network, and can be programmed to trigger actions based on specific events or conditions.

It is important to note that as the technology and understanding of blockchain is evolving rapidly, new research and literature is being produced frequently. Google is showing the recent trends in the Health Information Exchange.

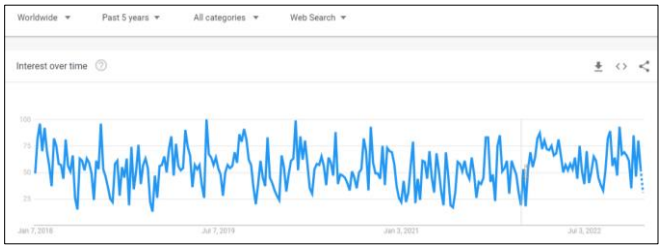

Figure1. Global Health Information Exchange (HIE) google trend analysis (Past 5 years 2018-2022)

In order to facilitate exchange agreements between hospitals, clinical areas, regulators, insurers, and even patients, HIE network organizations have developed. They guarantee to offer genuine integrated health systems with support for Electronic Health Records (EHR). The evidence that is now available continues to point to these systems' incapacity to satisfactorily serve stakeholder demands. This present architecture has been under fire for being opaque and having a centralized authority for failure, attack, and ownership. Through intentional or unintentional behaviors of these intermediaries, a lack of confidence regarding the security and privacy of entrusted patient information is growing [4].

Figure 2. Global Health Information Exchange (HIE) google Countries wise trend analysis.

A. Blockchain In healthcare

1) Study Rationale

The trust gap prevalent in conventional HIE continues to be revealed as a result of competing interests, the inability of traditional HIE and PHR-based exchanges to deliver on the promise of a shared, integrated EHR, and a number of other factors. This distrust has grown as a result of privacy regulations and data breach incidents. Stakeholders are reluctant to cooperate or collaborate at the levels necessary for shared value as a result. The effect is lower health outcomes and rising healthcare expenses. Figure 1 shows the Google patterns over the past 20 years, which may help to

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understand why HIE has attracted attention consistently over that time [4][5].

If this tendency is a clear indicator of contemporary global interests in Figure 2 it follows that these difficulties persist despite ten years of technical progress. We speculate that one major reason for the lack of advancement may be the trust gap. Blockchain is currently being used by researchers to assist solve some of these trust-related problems. The rising surge of interest in blockchain in healthcare has been stoked by this and a number of other factors.. The study in [4] was commissioned to learn more about this field of study and how it has developed.

2) Prior System Architectures

The following two prior Ethereum based architectures have been analyzing because the recent blockchain usage is primarily based on Ethereum due to its smart contract-based technology. The properties of the mentioned architectures are far better than the previous blockchain based architecture in previous years. These two are the latest to smart frameworks which are managing the data for health records. Data sharing that is both secure and scalable is necessary for group clinical decision-making. However, conventional clinical data initiatives are frequently segregated, which obstructs effective information interchange and hinders treatment decisions for patients [5].

The following restrictions apply to the Ficain DApp because it was created using various presumptions:

- Has no mention of semantic interoperability. The semantic interoperability problems that the FHIR standards have not yet completely accounted for cannot be solved by FHIRChain. Therefore, manual examination and mapping of preset ontologies by professionals in the fields of medicine and health data are needed to offer semantics to clinical data, and this will continue to be the major topic of our future research in this area.
- With older systems that do not support FHIR, compatibility issues might arise. Many historical systems may employ other communications norms, such as the more widely used HL7 v2 norms.
- It cannot prevent medical malpractice. Clinicians who are interested in working together to provide clinical decision assistance for patients in remote locations are the target users of FHIRChain. Our present design assumes that users won't abuse, mishandle, or unethically disseminate the data they communicate over our DApp.

- deployment fees for DApps. Contrary to popular public blockchains like Ethereum, our DApp is created utilising a private testnet with no transaction fees (e.g., transaction fees). Therefore, if our DApp was made available on a public blockchain, it would not be free. However, the ease of use offered by a public blockchain may make it more affordable to use than it would be to buy, operate, and maintain a proprietary clinical data exchange infrastructure [5].

The architecture, known as Ancile [6], combines smart contracts on an Ethereum-based blockchain for improved access control and data obfuscation in addition to advanced cryptographic techniques for added safety. In order to understand how the framework could address chronic privacy and security challenges in the healthcare industry, this article will look at how Ancile interacts with the diverse expectations of patients, providers, and other parties. Multiple parties may safely interact with the blockchain and its data thanks to Ancile. Ancile prioritizes secure contact, therefore the architecture we provide contains a number of additions intended to boost privacy and interoperability. The Ancile blockchain, in contrast to other blockchain EHR systems that have been developed, first maintains hashes of the data references while transferring the actual query link information in a private transaction via HTTPS.

The patient's ownership rights are the main emphasis of design. As a result, our design adheres to the notion that the patient owns the data and that it is not a commodity to be traded. As a result, Ancile does not include any mining incentives beyond the requirement to utilize the system.

We believe that governments and service providers already have an incentive to protect patient medical information. On the blockchain, we also take into consideration the various roles played by patients, providers, and third parties by using smart contract capabilities for access control. This enables the stratification of jobs to better serve the various demands of users [12].

It is important to note that many of the technologies used in the proposed Ethereum-based healthcare framework, such as permissioned blockchains and smart contracts, are still in the early stages of development. Therefore, the success of the framework is highly dependent on the success of these technologies. It should also be noted that the proposed solution, Ancile, should not be seen as a complete solution to the larger issue of Electronic Health Record (EHR) security. While it provides a method for re-encrypting a symmetric key using proxies selected by the patient in a pseudo-random manner, compliance with legal requirements for medical data and patient privacy protection requires that the proxy group and RC must have been formed beforehand using blockchain technology. Now that we know that blockchain technology is suffering from scalability issue Anicle [6], wouldn’t recommend solution.

The PHR blockchain architecture created in this study provides an effective solution for the management and usage of PHRs. The platform was originally presented in Southeast Asian countries through the Asia eHealth Information Network, [7] and it is currently the first PHR management platform for cross-regional medical data exchange (AeHIN).

In order to transmit, store, and share PHR data securely between patients and medical healthcare providers, a blockchain-based PHR exchange architecture and management platform was developed. Among its features are the ability to see PHRs for personal health management, exchange PHRs with a physician, and perform security checks on blockchain data. The PHR administration component's user interface has also been developed.

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IV. PROPOSED HEALTH RECORD MANAGEMENT PLATFORM BLOCKCHAIN BASED KAFKA SMART CONTRACT HASH ARCHITECTURE

The study saved smart contract hash values in a blockchain to safeguard the PHR data and verify the accuracy of the PHR contents since blocks in a blockchain cannot be tampered with or maliciously altered. The blockchain architecture employed was Ethereum's private chain, and the Ethereum protocol's Geth (Go Ethereum) application was used to move transactions from the proposed platform to the blockchain exchange framework, produce new blocks, and establish a connection to the blockchain. as seen in Figure 4.

The data are encrypted while being transmitted over the network to prevent private information from being compromised. To protect the user's privacy, the platform encrypts the health record before uploading it to the safe database. A malicious attacker will only succeed in getting a set of random numbers if they try to access the block content. The encryption process combines asymmetric encryption with hash encryption. The block content is secured using a hash encryption method that transforms data into a collection of hexadecimal characters using SHA-256[9][13].

For scalability of data on the blockchain Apache Kafka has been introduced. The data blocks in the super peer's network are distributed using the Apache Kafka platform. By expanding its producer and consumer classes, which represent client nodes delivering and receiving data locks, respectively, Kafka abstracts application concerns about data replication [10][14][15].

To understand the dynamics of the apache Kafka and components the Figure 3 is displaying.

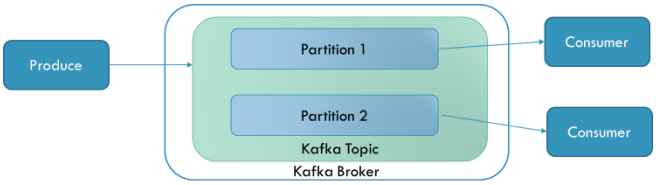

Figure 3. Apache Kafka Structure

Below Figure 4 shows the architecture of the Apache Kafka build Ethereum blockchain. The most well-liked distributed publish-subscribe messaging system is Kafka. Topics, brokers, producers, and consumers make up it. Topics are how Kafka groups a stream of messages. The producer sends out streaming messages, which are then retrieved by the consumer. One or more servers, referred to as brokers, make up a Kafka, which collects and stores data reliably before publishing relevant topics. Kafka cluster node status is monitored using Apache Zookeeper. A broker receives messages from producers. The customer obtains this information without any loss, and the broker retains it. (Performance Evaluation of Intrusion Detection Streaming Transactions Using Apache Kafka and Spark Streaming).

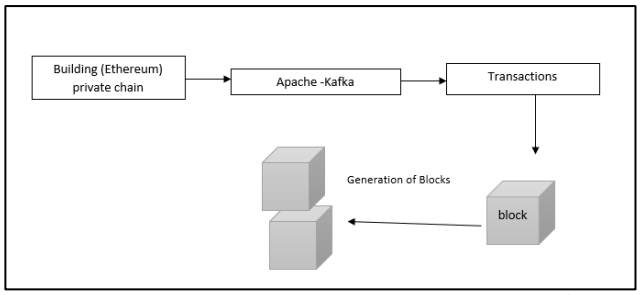

Figure 4. Proposed Private Blockchain built with Apache Kafka

Fast in-memory processing is offered by Apache Kafka. It is a flexible tool for a wide variety of large data processing applications since it is appropriate for both batch and streaming data.

These activities consist of interactive big data searches, graph processing, and machine learning [11]. Apache Kafka will increase effectiveness: The speed of block formation is increased, and waiting times for data interchange are decreased. extremely scalable and compatible: Additionally, intelligent collaborative construction may be finished.

While Apache Kafka is a powerful tool for real-time data processing, it is important to carefully consider its potential disadvantages, particularly in terms of system complexity, security, and message reliability, when evaluating its use for specific applications. Potential disadvantage is the complexity of configuring and managing a Kafka cluster. Setting up a Kafka cluster requires a deep understanding of the underlying system architecture, and can be challenging for organizations with limited technical expertise. In addition, Kafka lacks robust monitoring and management tools, which can make it difficult to diagnose and resolve issues when they arise.

Kafka's reliance on a publish-subscribe messaging model can sometimes result in message loss or duplication. While Kafka provides mechanisms for handling these issues, they can add additional complexity to the system architecture and require careful configuration to ensure reliable data processing.

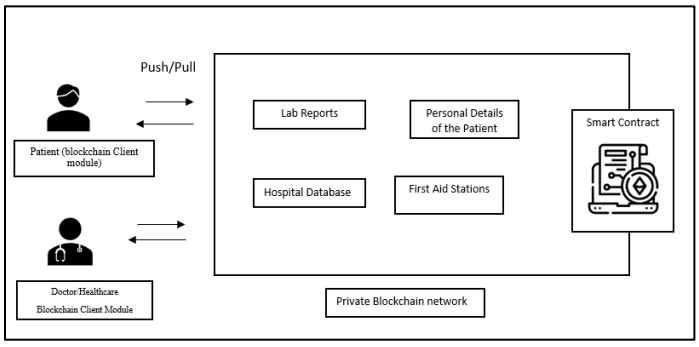

Figure 5. Proposed personal health record blockchain based Framework

V. PERFORMANCE METRICS

Blockchain security can be measured by various performance metrics. Some commonly used metrics to evaluate blockchain security include:

Decentralization: This metric measures the distribution of control within a blockchain network. A more decentralized network [2][3] is considered more secure as it is less susceptible to a single point of failure.

Consensus mechanism: This metric measures the method used to reach agreement on the state of the blockchain.

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Different consensus mechanisms have different security properties, and some are considered more secure than others.

Hash rate: This metric measures the computational power of a blockchain network, and is an indicator of the security of the network against a 51% attack.

Network size: This metric measures the number of nodes in a blockchain network, and is an indicator of the security of the network against a Sybil attack [3].Network size will be easier to maintain.

Smart contract security: This metric measures the security of the smart contracts that run on the blockchain. Smart contracts can have vulnerabilities that can be exploited by attackers, so it is important to ensure that they are secure.

Auditing and testing: This metric measure the extent to which the codebase of the blockchain is audited and tested for security vulnerabilities [4]. It is important to note that security is a complex and multifaceted issue, and no single metric can fully capture it. Therefore, it is important to consider multiple metrics to get a comprehensive understanding [8] of the security of a blockchain.

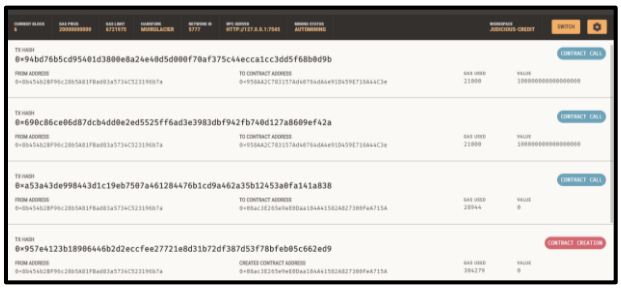

Figure 6. Blockchain generated Smart Contracts and contract calls on Ganache

Blockchain technology as in Figure 6, some transactions were done to implement private blockchain and it is often considered to be a secure and private way to conduct transactions, but there are certain factors that can affect the privacy of a blockchain network. Some performance metrics that can be used to evaluate the privacy of a blockchain include:

Anonymity: This metric measures the degree to which users are able to hide their identities on the blockchain. Anonymity can be achieved through techniques such as zero-knowledge proofs, ring signatures, and coin mixing.

Confidentiality: This metric measures the degree to which the details of transactions are kept private. Confidentiality can be achieved through techniques such as confidential transactions and zero-knowledge proofs.

Traceability: This metric measures the degree to which the transactions on the blockchain can be traced to specific individuals. Some blockchain networks, such as Bitcoin, have a high degree of traceability, while others, such as Monero, have been designed to provide a high degree of privacy.

Scalability: This metric with use of Apache Kafka will increase 6 times to manage the implementation with proposed framework.

Network analysis: This metric measures the degree to which the blockchain network can be analyzed to reveal information about the users and their transactions.

Data protection and encryption: This will potentially increase 80 times increasing the data protection via Apache Kafka. This metric measures the level of data protection and encryption implemented in the blockchain network to ensure the privacy of the data.

It is important to note that even though blockchain technology has some features that ensure privacy and security, it is not completely private. There are also other factors that can affect the privacy of a blockchain, such as the regulatory environment and the use of third-party services.

VI. DISCUSSION

This framework A blockchain-based personal health record (PHR)/EHR system has the potential to transform the PHR/EHR industry by providing a secure, decentralized, and tamper-proof way to store and share health information.

One of the main benefits of using a blockchain for PHR is the increased security it provides. Blockchain technology is inherently secure, as it uses advanced cryptography to ensure that once data is entered into the blockchain, it cannot be altered or deleted. This would help to prevent unauthorized access to sensitive health information and protect patients' privacy. Additionally, a blockchain-based PHR system would allow patients to have full control over their health data, enabling them to share their records with medical professionals and other authorized parties as needed. This would reduce the need for paper records and improve the speed and efficiency of care. Another potential benefit of using a blockchain for PHR is that it would enable the creation of a decentralized network of health data, allowing for better data sharing and collaboration among healthcare providers. This would enable healthcare providers to access a patient's complete health history, which could help to improve patient outcomes and reduce healthcare costs.

However, it is important to note that this technology is still in its early stages and there are still several challenges that need to be addressed such as data privacy, data security, interoperability, data sharing regulation and standardization.

We have created smart contracts and also worked on the Ethereum blockchain build with Apache Kafka where the scalability issue can be solved for the Ethereum blockchain in-case of wide adoption of the blockchain technology.

Work is in progress to create a complete interface for implementation of the proposed methodology majorly work remaining on the UI/UX off the health application and connecting the Ethereum blockchain build with Kafka and then the smart contracts with personal health records are saved in the

VII. CONCLUSION

Blockchain-based architecture is a distributed database system that uses a chain of blocks to store data in a decentralized manner. This architecture is highly secure, transparent, and immutable, making it useful for a wide range of applications. However, one of the main challenges with blockchain-based systems, including Ethereum, is scalability. This is due to the consensus mechanism, which requires all nodes in the network to process every transaction. To address this challenge, our proposed

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framework combines Ethereum with Apache Kafka, a highly scalable and high-performance messaging platform.

The key features of our proposed architecture include decentralization, scalability, immutability, security, and transparency to increase potentially 6 times than the current available solutions. Decentralization ensures that the database is distributed across a network of computers, making it difficult for any one party to manipulate the data. Immutability ensures that once data has been added to the blockchain, it cannot be altered or deleted, ensuring the integrity of the records. Security is ensured through the use of cryptographic techniques, which prevent unauthorized access to the data. Transparency is provided by recording all transactions and changes to the database, which can be viewed by all parties.

Our proposed framework uses Apache Kafka as the underlying messaging platform for the Ethereum-based blockchain system, which offloads some of the workload from the Ethereum nodes and distributes it across a Kafka cluster. This improves the scalability of the system, allowing it to handle large volumes of data in real-time.

In summary, the use of a blockchain-based architecture can help to create secure, transparent, and decentralized record-keeping systems. Our proposed framework addresses the scalability challenge of Ethereum by using Apache Kafka, making it useful for a wide range of applications

VIII. FUTURE DIRECTIONS

Our proposed blockchain-based Personal Health Records (PHR) framework has several important points that make it a suitable candidate for full implementation:

Firstly, PHRs are critical for the foundation of precision medicine, which is the future of healthcare. Our PHR framework has the potential to be implemented on a large scale due to its scalability feature, which enables PHRs to be exchanged between nations and allows for potential precision medicine uses in the future. Secondly, financial data management systems have already successfully employed blockchain technology to secure data security and privacy. With improved system specifications and a greater private blockchain, work can be done to scale the framework and improve the user interface and user experience. Thirdly, the current global operations require the development of a cross-country medical care infrastructure, and our proposed blockchain-based PHR framework can play a significant role in this infrastructure. Lastly, by building the blockchain on a sidechain with better system specifications, we can yield better results, and smart contract transactions can be managed more effectively.

Overall, our proposed blockchain-based PHR framework has the potential to revolutionize the healthcare industry by providing a secure, transparent, and decentralized record-keeping system for patients' medical records. It is now time to move forward with full implementation of the proposed methodology.

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Patient Experience with Non-Clinical Aspects of Virtual Clinics: Beyond User Experience Design

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***Abstract*—eHealth practices bring many opportunities to the healthcare sector, such as increasing accessibility to healthcare services while controlling cost and resource allocation. Virtual clinics are one of the essential components of the eHealth system. Virtual clinics have been widely implemented, especially during the Covid-19 pandemic and after it. Hence, it is important to evaluate patient satisfaction with the quality of the care services provided by those clinics. Many studies attempted to evaluate the patient experience with virtual clinics from the angle of user interface design and user experience when interacting with virtual clinics applications. However, there is a lack of studies investigating patient experience and satisfaction regarding non-clinical aspects that are related to clinical tasks in the context of virtual clinic applications. Hence, the main objectives of this study are to evaluate patient experience with non-clinical aspects of virtual clinics using a standardized tool and analyze opinions of multi-perspectives of users (patients, physicians, and software engineers) to enhance patient experience design regarding the non-clinical aspects. This study utilized the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) survey to evaluate patient satisfaction with non-clinical aspects of virtual clinics. In addition, a focus group session was conducted to collect data on the issues related to non-clinical aspects and how to resolve those issues and enhance the patient experience when designing virtual clinics. The results showed that participants are generally satisfied with the quality of communication with doctors in virtual consultations and with using the virtual clinics overall. However, participants have a negative experience regarding information availability of patient health record and medicines and their side effects. Moreover, the participants of the focus group session emphasized the importance of enhancing human communication and integration of human value when designing virtual clinic applications, and providing better support after the online session is over.**

***Index Terms*—Software Engineering; Healthcare; eHealth; Patient Experience.**

I. INTRODUCTION

Patient satisfaction has been one of the essential dimensions to evaluate the quality of provided healthcare services [1]. Patient satisfaction evaluates the perception of patients about the quality of the provided services. If the quality of provided services do not match patient expectations, patient satisfaction is expected to the low. Patient experience (PX) is another concept that evaluates patient experience before, after, and during receiving healthcare services [1]. The Beryl Institute defines the patient experience as *"the sum of all interactions, shaped by an organization's culture, that influence patient perceptions across the continuum of care"* [2]. However, a unified, clear, and standardized definition of PX does not exit yet, which makes measuring and evaluating PX a challenging task [3].

The rapid implementation of digital health transformation and the wide adoption of virtual clinics applications lead to a new concept called Digital Patient Experience (DPX). In current literature, PX or User Experience (UX) are used interchangeably with DPX as a specific definition of DPX is still missing [4]. Studies conducted about DPX focused on understanding factors and components that influence DPX. Those factors are clinical and non-clinical aspects of virtual clinics applications. Examples of the non-clinical aspects are the usability of virtual clinic applications (user interface, personalization, profiling, readability, etc.) [4]. An example of non-clinical aspects that are associated with clinical tasks is communication with doctors [5]. Most studies conducted to evaluate PX with virtual clinics focused on evaluating the technical part of virtual clinics (usability and user interaction). Despite the fact that DPX has its own nature compared to the PX in physical visits, there is a paucity of literature that evaluate the other non-clinical aspects of virtual clinics, such as communication with doctors, information availability, and medicines explanations.

In this study, we attempted to evaluate PX regarding the non-clinical aspects of virtual clinics using a customized version of the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) survey. In addition, we conducted a focus group session that brought multiple perspectives of users (patients, physicians, and software engineers) to have a deep analysis of their reactions regarding the non-clinical aspects, and to collect their input on how to improve the non-clinical aspects and the overall PX when using virtual clinics.

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We believe that this study contributes to the body of knowledge by 1) using a standardized tool to evaluate PX regarding non-clinical aspects on virtual clinics, and 2) establishing a multi-perspective analysis of PX regarding non-clinical aspects of virtual clinics that is reported to be missing in literature [5]. The results showed that patients are satisfied with virtual clinics in general and when the medical case is not urgent. However, to improve patient experience, participants mentioned that human communication, incorporation of human values, and adequate support services after the consultation need to be enhanced.

The rest of the paper is organized as follows. Section II provides background about the evaluation of patient satisfaction and experience factors and tools. Section III illustrates the research methodology followed in this work. Section IV presents the survey and focus group results. Lastly, Section V discusses the findings of the study, and Section VI draws conclusions and discusses some future research opportunities.

II. Related work

There are many studies that attempted to evaluate and investigate what influences patient satisfaction. One of the most widely used and approved tools is the HCAHPS survey (https://www.hcahpsonline.org/). It assesses nine aspects of patient perception of the hospital environment and the quality of the provided care that are communication between doctors and nurses, the responsiveness of hospital staff, pain management, communication about medicines, discharge information, hospital environment (cleanliness and quietness), and transition of care. Kuper and Bonds argued that is true that patient satisfaction is strongly correlated with their expectations about healthcare services (the quality of services); however, there are multiple factors that impact patient satisfaction, such as the environment, culture, pain, healthcare providers, etc. [6]. In addition, Weston and Robers [7] indicated that access to healthcare providers' teams increases patient satisfaction. Another study confirmed the same that patient interaction with the healthcare teams is strongly associated with patient satisfaction [8] [9]. Gualandi et al. [10] investigated patient experience while exploring the hospital patient journey. They found that the significant issues that impact patient experience are lack of information, patient/professional relationships, family closeness, and efficient integration of clinical-related tasks.

In terms of e-health, Wang et al. [4] found that the digital patient experience is influenced by many factors, such as personalization of patient profile, availability of information (health information and educational material, communication and accessibility to professionals, functionalities such as reminders, rewards, etc.), and visualization and navigation. The study emphasized the lack of knowledge about the digital patient experience. In addition, it highlighted the absence of multiple perspectives (such as healthcare professionals, patients, designers, etc.) when designing digital patient experience. Clinician perspectives of e-health are absent, and real interaction between designers and patients when designing e-health applications is not available [11] [12]. Vitanen et al. [5] conducted an SLR to investigate the factors that influence PX and their components. Some of the factors are the support of e-health care processes (communication, remote interaction, and risks and concerns with e-health applications), and the quality of eHealth solutions that include usability, accessibility, and readability issues.

For conducting the evaluation of DPX, most of the existing studies focused on evaluating the technology part of virtual clinics by conducting usability studies. Broekhuis et al. [13] proposed an ontology of usability issues of eHealth applications from the perspective of users. Alkhomsan et al. [14] emphasized the importance of incorporating patient emotions into virtual clinics desing as emotions play a pivotal role in patient acceptance of eHealth technologies. Other studies focused on evaluating patient experience [15] [16] and the usability of virtual clinics [17] [18] during the Covid-19 pandemic.

The related work showed that existing studies either discuss what constitutes PX or evaluate the virtual clinic applications from the usability and technology aspects only. Hence, in this study, we attempted to fill the gap by evaluating the quality of non-clinical aspects of virtual clinics, other than the technical aspects, from the perspective of patients. Also, we performed a focus group session to bring multiple perspectives of patients, doctors, and software developers to evaluate and suggest how to enhance PX with virtual clinics.

III. Study Methodology

In order to achieve the research objectives, two research methods were applied that are survey and a focus group. The following sections explain each research method in detail.

A. Survey

The survey method was selected to collect data on patient experience with non-clinical aspects of virtual clinics. Yet, there are no clear measures to measure PX; however, it is claimed that patient satisfaction and patient perception contribute to patient experience [6] [19]. Hence, this study customized and utilized HCAHPS survey, which is known to be the stander tool to collect data on patient experience regarding the non-clinical aspects. HCAHPS survey covers all non-clinical aspects that have been discussed in the relevant literature. However, in this study, HCAHPS was customized to suit the nature of virtual clinics as the HCAHPS is intended to be used with physical visits to hospitals. The original survey is found online(https://www.hcahpsonline.org/). For our study, I attempted to map the factors, see section II, that HCAHPS evaluates, after an actual stay of the visit to hospitals, to the virtual clinics' context. All factors of the HCAHPS suit the virtual clinics except for two: the hospital environment aspect that corresponds to the virtual clinic application design and communication with nurses that does not exist in most virtual clinics. Hence, both factors were eliminated. For communication with nurses, in most virtual clinics that replaces regular visits to the hospital nurse role does not exist. The reason for the elimination of non-clinical aspects related to

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technical design aspects is that many studies have already covered and focused on this part. In addition, the design of virtual clinics may vary from one application to another which will lead to an inaccurate evaluation in general. In this study, we focus on the non-clinical aspects that are related to clinical activities. The customized version of the survey is available online(https://forms.gle/4QFYjGgufev83LrB6). Those aspects are going to be the main focus in the focus group session as well.

The survey was distributed by email invitations using a randomized snowballing technique. We received 20 complete responses. All participants used virtual clinic applications at least once. In addition, in terms of participants' educational background, most of the participants have more than 4-year college degree, while four are four years college graduates and one has an 8th grade or less. All participants are in an excellent or a good state of health and mental health.

B. focus group

The focus group enables a thorough understanding and deep analysis of a group of users' reactions to a common experience. Hence, we conducted a focus group session that brought rich and diverse perspectives of patients, physicians, and software development experts about the following topics:

- **Motivations of using virtual clinics**: what are the motivations for using virtual clinics instead of actual visits?
- **Communication - Doctors' Respect and courtesy**: how patients evaluate it and it could be enhanced.
- **Data and information availability**: what are the data and information that are important to have available all time and what is the best way to present it?
- **Medicines and symptoms**: what is the best way to get information on medicines and patient symptoms? health conditions explanations
- **Follow ups**: what is the best way to get follow-ups?
- **Absence of nurse role**: does it impact the experience negatively or positively?
- **Overall improvements**: How to improve overall patient experience of non-clinical aspects when using virtual clinics?

The session lasted for an hour. The participants in the session are four patients, a software development expert, and a physician. All participants have either bachelor degree or higher. The age of participants ranged from 28 to 40.

IV. RESULTS

This section reports on the study findings.

A. Patient satisfaction regarding non-clinical aspects

Table I illustrates the participants' responses to the non-clinical aspects of virtual clinics that are communication with doctors, experience during the virtual clinics in terms of medication explanation, experience after leaving the virtual clinics in terms of information availability (patient medical case and responsibilities to manage their health), and overall experience.

1) ***Communication with doctors****:* Regarding communication with doctors, more than half of the participants indicated that they were always treated with respect and courtesy during the virtual consultations. The majority of participants felt that doctors always or usually listened to them carefully during the virtual visits. However, five responses indicated that doctors sometimes listened to them carefully. Around 12 participants indicated that doctors always or usually explain things in a way they can understand. But the other responses are negative about the way doctors explain things clearly.

2) ***Experience during the virtual clinics: Medication Explanation****:* The participants' reactions to the explanations they received about their medicines were divided equally into positive (always and usually) and negative (sometimes and never). In addition, most of the participants (6) indicated that they were not informed about the side effect of their medications, or they were informed sometimes (8).

3) ***Experience after leaving the virtual clinics: Information availability and understanding the patient care****:* In terms of information availability, 13 participants indicated that they did not receive information about what symptoms or health problems to look out for after they left the virtual consultations. In addition, almost all participants (15) mentioned that they were not contacted by the healthcare team after the virtual clinics to ask if they found the support/help they needed. Moving to understanding patient care, most participants agreed that when they left the virtual consultation, they had a good understanding of how to manage their health. In addition, half of the participants mentioned their preferences and those of their families or caregiver into account in deciding on the treatment plan.

4) ***Overall experience with virtual clinics****:* The participants were asked to rate their overall experience with virtual clinics on a scale from 1 to 10, where one is the worst and ten is the best. Five participants rated four, five rated six, five rated 7, one rated 9, two rated 10, and two rated 2. The participants' opinions about not recommending the virtual clinics over the actual visits to their family and friend vary. Also, they sometimes prefer virtual consultations over actual visits. Six participants left comments on the major issues of virtual clinics that affect patient experience and satisfaction negatively. The major issues are poor examinations, lack of physical examination, poor communication, and lack of information and follow-ups.

B. Focus groups

The focus group covered four main topics: motivations for using virtual clinics, communication with doctors, availability of information (patient health records, and medicines), follow-ups and the role of nurse, and general improvements suggestions.

1) ***Motivation for using virtual clinics****:* The participants mentioned that they use virtual clinics mainly in four cases that are when they do not have time for actual visits, when they need medicines to refill only, when they want to get an initial consultation on non-urgent or non-critical symptoms,

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and when they have minor health issues, such as cold or flu. However, the physician mentioned that most of the cases are about acquiring sick leave report.

*2) **Communication with doctors**:* This part started by asking the patients the following question: how do you know that a doctor listened to you carefully and treated you with courtesy in a virtual consultation? Two participants mentioned that when doctors have follow-up questions, they feel that he or she was listening and caring about their case. Also, other participants mentioned that when a doctor read their health record before the start of the consultation, it is a sign that the doctor respects them. Other signs said are using video calls and making eye contact, voice tone, and understanding patients' questions. Then, all participants were invited to suggest how to enhance patient experience regarding communication with doctors. Two participants mentioned that video calls should be mandatory. The physician also suggested using video calls may partially eliminate the negative impact of the absence of face-to-face communication. However, the technical expert indicated that mandating video calls for both doctors and patients is not feasible as some patients do not prefer to open the camera. The solution might be for doctors to open the camera.

*3) **Information availability**:* All participants agreed that the availability of information regarding patient health symptoms or medicines and their side effects is important. The participants (patients) mentioned that they need the health record to be used in future actual or virtual visits on different platforms. They request that the report of patient health symptoms, diagnosis, and medicines should be shared with the patient right after the virtual consultation. In addition, information about the medicines, how to use them, and what are the expected side-effect is also essential to be available. However, one participant (patient) mentioned that she does not want to know the side effect as this may influence her perception of the medicines negatively and may lead to unreal feelings of side effect symptoms. It was suggested by the technical expert to have all medicines, their explanations, and side effects to be available online after the consultation session. In addition, it was suggested to use a chatbot to introduce patients to medicines and answer their questions. All participants agreed on this solution as long as they could customize the level of details of the provided information by the chatbot. However, the physician did not agree with this solution, as medicines and their related explanations should be monitored and provided by certified practitioners.

*4) **The role of nurse and follow-ups**:* All participants agree that the absence of the nurse role does not affect the virtual clinic experience. However, an assistant is needed to provide the required support before and after the consultation. One participant (patient) suggested using chatbots to interact with patients before and after the virtual consultations. Chatbots also can do follow-up communications. Alternatively, follow-ups could be done by phone calls.

*5) **General improvements suggestions**:* Participants mentioned that chatbots are acceptable solutions to solve most communication and needed support issues. However, two participants (patients) mentioned that technology should not override the role of human communication. Effective human communication with empathy and understanding should be incorporated into the design of virtual clinics. In addition, One participant (patient) mentioned that trust and human values should be a part of the virtual clinics' design. The physician mentioned that those technologies should be designed to suit all ages of patients with different educational backgrounds. Also, it was suggested that for elderly or under 18 patients, a family member could be allowed to attend the virtual consultations. Three participants suggested having evaluation records for each healthcare provider, and the evaluation should be visible to patients to increase trust in the provided care through virtual consultations. Moreover, a brief introduction of the healthcare providers should be available before the session. For this, a short video of the bio and experience of the healthcare providers could be provided to patients. The physician suggested that there should be new performance evaluation metrics when it comes to virtual clinics. The metrics shall provide means to evaluate the quality, not the quantity only, of the provided care services from a clinical perspective. TableII summarized the recommendations to improve DPX using virtual clinics from the perspective of the focus group participants.

V. Discussion

The study attempted to provide an understanding of patient satisfaction and experience regarding the non-clinical aspects of virtual clinics. First, the HCAHPS was customized and used to collect the required data. With the absence of standardized evaluation tools for patient satisfaction with non-clinical aspects of virtual clinics, we found an opportunity to explore the use of HCAHPS tool in evaluating patient satisfaction with virtual clinics. The findings of the survey were consistent with the result of the focus group session. As participants in the focus group session tend to provide observations and discussion points that are covered by the survey. However, there is a need to examine the effectiveness of this tool in evaluating patient satisfaction with virtual clinics empirically and customize it accordingly.

In the survey results, it was noticed that most participants who are always satisfied with virtual clinics used virtual clinics that are provided by a private healthcare provider, while the ones who are less satisfied used virtual clinics provided by the public healthcare sector. Another observation is that most of the participants who mentioned that they were not given a new medication, used virtual clinics for follow-ups and medication refills. Moreover, participants who have a positive experience with the medication explanations during the virtual clinics share the same opinion as other participants that the side effects of the medications were not explained to them.

The result of the survey and the focus group confirmed that information availability is a big issue as it received the most negative reactions among all non-clinical aspects. In addition, assuring that the patient received all help before and after

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TABLE I
PATIENT SATISFACTION WITH NON-CLINICAL ASPECTS OF VIRTUAL CLINICS

Communication with doctors	Always	Usually	Sometimes	Never
During the virtual consultations, how often did doctors treat you with courtesy and respect?	12	4	4	0
During the virtual consultations, how often did doctors always listen carefully to you?	9	6	5	0
During the virtual consultations, how often did doctors explain to you things in a way you could understand?	6	6	2	2
Experience during the virtual clinics: Medication Explanation	Yes		No	
During the virtual consultations, were you given any medicine that you had not taken before?	11		9	
	Always	Often	Sometimes	Never
Before giving you any new medicine, how often did doctors in virtual clinics tell you what the medicine was for?	4	6	6	4
Before giving you any new medicine, how often did doctors in virtual clinics describe possible side effects in a way you could understand?	3	3	8	6
Experience after leaving the virtual clinics: Information availability and understanding the patient care	Strongly agree	Agree	Disagree	Strongly disagree
When I left the virtual consultation, I had a good understanding of the things I was responsible for in managing my health.	3	13	2	2
When I left the virtual consultations, I clearly understood the purpose for taking each of my medications.	3	10	2	2
	Yes		No	
After the virtual consultations, did doctors, or other virtual clinics staff talk with you about whether you would have the help you needed when you left the virtual consultations?	5		15	
During or after the virtual consultations, did you get information in writing about what symptoms or health problems to look out for after you left the virtual clinics?	7		13	
Overall experience with virtual clinics	definitely yes	probably yes	probably no	definitely no
Would you recommend this virtual clinics over actual hospital to your friends and family?	6	7	5	2
	Strongly agree	Agree	Disagree	Strongly disagree
During the virtual consultation, doctors took my preferences and those of my family or caregiver into account in deciding what my health care needs would be when I left.	2	7	6	3

TABLE II
SUMMARY OF THE RECOMMENDATIONS OF THE PARTICIPANTS IN THE FOCUS GROUP SESSION

Participant	Recommendation
Patient	• Read patient health record before the consultation • physicians should use video calls, make eye contact, and use appropriate voice tone • provide a report of patient health symptoms, diagnosis, and medicines • use chatbots to interact with patients before and after the virtual consultations • effective human communication with empathy should be incorporated into the design of virtual clinics • trust and human values should be a part of the virtual clinics' design • a family member should be allowed to attend the virtual consultations • have evaluation records for each healthcare provider to be viewed by patients • a short video of the bio and experience of the healthcare providers could be provided to patients
Technical expert	• have all medicines, their explanations, and side effects available online after the consultation session • Use chatbots to answer the patients' questions about medications
Physician	• technologies should be designed to suit all ages of patients with different educational backgrounds • provide new performance evaluation metrics for virtual clinics that captures the quality of services not quantity only.

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the virtual clinics was missing. This could be solved by the solutions suggested in the focus group, such as chatbots or phone calls. In the focus group session, participants gave many solutions to enhancing patient experience with non-clinical aspects of virtual clinics. Technical-wise, all solutions are visible. However, the participants' acceptance, including the physician, varies about those solutions. Most of the participants suggested that patient experience will be enhanced when effective human interaction and communication are incorporated into the design. In addition, there was a demand to incorporate human values, families, and preferences into the clinical processes of virtual clinics.

Despite the potential benefits of this study, there are limitations that are worth mentioning. This study is only preliminary that intended to explore using HCAHPS survey and multi-perspective focus group sessions to enhance patient experience with non-clinical aspects of virtual clinics. However, the validity of using the HCAHPS survey in the context of virtual clinics is not validated yet. In addition, the size of participants in the survey and the focus group session is small, and the participants have good mental health in general. Hence, the results of this study could not be generalized. Moreover, in this study, the focus was on non-clinical aspects of virtual clinics with the exclusion of the technical part evaluation, such as user interface design, which may impact the analysis of the results and the participants' reactions.

VI. Conclusion

This study attempts to evaluate patient satisfaction and experience with non-clinical aspects of virtual clinics. The HCAHPS survey was customized and used to evaluate patient satisfaction, while a multi-perspective focus group session was conducted to explore how to enhance patient experience about non-clinical aspects. The survey findings showed that patients have a positive reaction toward non-clinical aspects of virtual clinics. However, the major issue was related to the information availability of patient health records, medication explanations, and receiving support after the end of the virtual consultations. In the focus group session, the participants illustrated acceptance of solving some existing issues by chatbots or other technology-related solutions. However, they also highlighted the need to improve human interaction and communication and to integrate human values into the design of virtual clinic applications.

For future studies, we plan to evaluate the validity and reliability of the customized version of HCAHPS survey in evaluating patient satisfaction with virtual clinics. In addition, a larger sample of participants, including patients who have mental health issues, will be recruited to ensure that the finding is generalizable and valid. Also, we plan to employ the design thinking approach with multi-perspectives participants to generate and evaluate new solutions in terms of enhancing patient experience with virtual clinics.

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Adolescents Experiences with Video Consultations in Specialized Mental Health Services in Norway

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***Abstract*—This project explored adolescents experiences with video consultations using a qualitative approach. Results from the study can be summarized in the six themes: 1) Therapy on the screen, 2) "Not for real" – The screen as a filter, 3) The screen as a "looking glass," 4) Emotions on the screen, 5) Therapy in a physical setting, 6) Tools for Therapy.**

Keywords-Video consultations; mental health; adolecents

I. INTRODUCTION

Historically, social relations and meetings between people usually took place in physical environments. During the last decades, the story is in a persistent change, and we have moved from the physical to the digital. It has given us new possibilities for communication, such as Video Consultations (VC) for adolescents within mental health services. Use of VC can potentially reduce problems related to traveling to the mental health care facility, as Norway consists of long distances and at times extreme weather conditions. The aim of this project was to provide knowledge about adolescent's experiences with the use of VC, and how the experience was compared to face-to-face meetings with their therapist.

The adolescents' experiences with VC are understood in light of Goffman's theory of frontstage and backstage, related to sense and impact of place or place-lessness. Goffman have been analyzing and describing situations when people interact with each other in physical settings, either frontstage or backstage [1]. Electronic media facilitate communication in real time between people who are in different places. In addition, we let us inspire by Actor-Network theory (ANT). ANT is used to study the relations between actors within a network, and how these relations change when a new actor (technology for VC) is introduced [2][3].

The methodological framework of the project is explained in Section 2, followed by a presentation of the results in Section 3, Section 4 consists of a discussion of VC for adolescents within mental health services, and finally conclusions and suggestions for further research in Section 5.

II. METHODOLOGY

33 individual interviews with adolescents between 16 and 23 years of age were conducted digitally between August 2021 and April 2022. The qualitative in-depth interviews were based on a hermeneutical-phenomenological perspective [4]. A semi-structured thematic interview guide was used during the interviews, which was made in co-creation between researchers and persons with user experiences.

Administration personnel at the local mental health facility identified adolescents that suited the inclusion criteria, which were as follows: 1) VC in the period from March 16th to August 5th, 2021. 2) Between 16 and 23 years old. A psychologist from the local facility contacted and asked potential informants by phone. The ones who said yes were contacted by a researcher to schedule an interview. None of the informants retracted after the interviews. All participants received written and verbal information about the study. Consent was sent by mail to the project leader and stored separately from any data material. The informants are anonymized.

The analysis of the interviews is inspired by an abductive approach [5]. It can be viewed as a cyclic process, which started during the transcription of the interviews.

III. RESULTS

The results reveal that the use of VC is a complex matter, and that adolescents are a heterogeneous group with different preferences and needs. The following six themes emerged during the analysis: 1) Therapy on the screen, 2) "Not for real" – The screen as a filter, 3) The screen as a "looking glass," 4) Emotions on the screen, 5) Therapy in a physical setting, 6) Tools for Therapy. The phenomena described within the themes are not discrete from another. The informants reported similar experiences with VC, but there were also individual preferences. The six themes are further elaborated below:

1) Therapy on the screen contains the difference between therapy and communication on screen versus in a physical setting. This includes difficulty and inhibition to talk about

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inner thoughts, not able to fully observe body language or to have eye contact.

2) "Not for real" – The screen is based on the perception of adolescents of VC as "unreal" and "less personal". They experienced that the screen removed something from the relation.

3) The screen as a "looking glass" describes the adolescents experiences with seeing their own image on the screen, and how this affected them during VC (distracting, challenging, triggering, etc.) The effect of your own image on the screen can be considered as the looking glass effect.

4) Emotions on the screen stems from several adolescents who told that it was difficult to show emotions on screen. They did not receive the necessary emotional support and closeness. One of the consequences was that they did not talk about difficult topics. Several of those reasons are highly intertwined with already presented themes. However, some talked more about difficult topics in a less personal medium.

5) Therapy in a physical setting is about the meaning of place, or lack thereof. Informants had experienced VC at home and/or at school. Their experiences differentiated based on surroundings at each location, for example fear that people would overhear versus feeling safe that no one would listen in.

6) Tools for therapy are about tools that are being used in a physical setting, for example a white board, which some of the informants missed during VC. Either because it could not be used, or because it was not optimal during VC.

IV. DISCUSSION

VC can in some cases bring new opportunities for understanding and treating illness in context, leading to a greater emphasis on psychosocial approaches.

Previous research on the use of VC shows that it can reduce travel-time, costs related to traveling to health care facilities and hours absent from school, and that trauma-experienced adolescents shared more relevant information during VC than in a physical consultation [6][7]. However, adolescents could experience disturbances when having consultations at home and the naturalness of the relation with the therapist was reduced, and the screen could become a 'barrier' for communication [7][8]. It is consistent with our findings, where the adolescents described the screen as a "not for real", the inability to read each other's body language on the screen, and how place and surroundings plays in.

Use of VC may be challenging to get a complete and complex understanding and knowledge about the users' situation in his or her context. This finding indicates a thorough assessment regarding use of VC. The adolescents in our study expressed that a combination of video and physical consultations was preferable. Their individuality and preferences should be considered when further developing and offering VC.

V. CONCLUSIONS

VC was a rapid solution during the international corona crisis. Norwegian health authorities aim to improve mental health services, and to broaden the offer of digital solutions for the increasing number of adolescents in need of mental health care [9]. VC have the potential to increase the availability and flexibility of mental health services for adolescents and their caregivers, including communication between adolescents and service providers. There is a need for further investigation on use of VCs, including qualitative and quantitative research, to build solid, evidence-based knowledge that can contribute to providing mental health care at a distance. Further research should focus on user experiences, organizational change, co-creation between stakeholders, and implementing VCs to offer safe and accessible services.

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Does Government Own Your Health Data?

A Case Summary of 2022 Taiwan Constitutional Court Decision

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Abstract—We all know personal health data is increasingly valuable; however, what is left behind is who can legitimately claim the ownership of the data and what rights and interest the owner can claim. A Taiwan Constitutional Court decision rendered on August 12, 2022 on one of the largest health databases in the world – the Taiwan National Health Insurance Database – provides us a real case on how the information privacy and data ownership issues, such as secondary uses, right to opt-out, and good governance mechanisms, can be argued, proposed, and regulated.

Keywords-Health Data; Seconary Ues; Information Privacy; Data Governance; Constitutonal Court; Taiwan.

I. INTRODUCTION

The Taiwan National Health Insurance Database (NHID) is a centralized and comprehensive database maintained by the National Health Insurance Administration (NHIA). The database contains a tremendous collection of over 70 billion health records from the country's 23 million population over the past 27 years [1].

While the original intent of creating the database was for health insurance management, such as payment, reimbursement, and quality improvement, the ever-lasting accumulating datasets, including patient demographics, medical diagnoses, treatments, prescriptions, and medical images like computerized tomography (CT) and magnetic resonance imaging (MRI), make secondary uses of the NHID incredibly valuable and appealing for both academic and commercial purposes. According to an NHIA's survey, more than 8,600 research papers have been published by using data from NHID [2].

The COVID-19 pandemic has accelerated the digitalization of health service delivery, and so does the commercial use of NHID. A Software Development Kit (SDK) program initiated by NHIA in mid-2019, under the My Health Bank (MHB) system (See Figure 1), has created a new channel for linking people's health data with mobile apps developed by private sectors. In other words, with authorization from member users and technical interference supported by the SDK, a third-party app developer now can combine its own user's data, such as running tracks or daily calorie intakes, with their users' personal medical records under NHID, such as cardiovascular diseases diagnose and treatment [1][3]. It certainly opens a route for a wide range of commercially secondary use of data on the NHID, such as chronic disease management or teleconsultation.

The paper is structured into three sections. Section I explains the NHID database and the secondary uses of the data, including commercial purposes, through the My Health Bank (MHB) system. Section II describes the legal disputes and proceedings of the lawsuit, including the plaintiffs' arguments and the defendant's counterarguments. Finally, Section III provides an overview of the Taiwan Constitutional Court decision on the NHID case, detailing the issues addressed and the Court's holdings and prevailing parties.

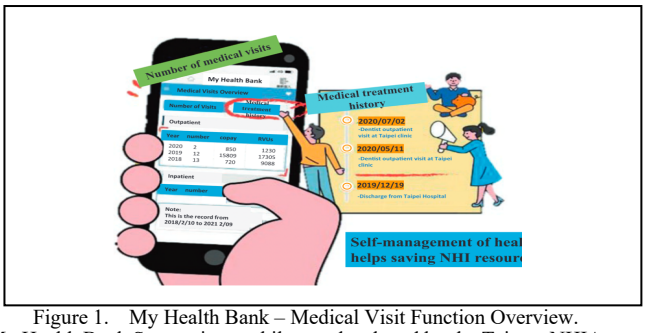

Figure 1. My Health Bank – Medical Visit Function Overview. My Health Bank System is a mobile app developed by the Taiwan NHIA to allow people access to their NHI data. [1]

II. LEGAL DISPUTES OF THE SECONDARY USES AND THE PROCEEDINGS OF THE LAWSUIT

Admittedly, despite the secondary use of NHID, such as research, policy development, public health surveillance, and even commercial innovation is so powerful, its legitimacy has been controversial and disputable under Taiwanese laws. In the spring of 2012, eight citizens from the Taiwan Association for Human Rights sent a cease-and-desist letter to NHIA for stopping providing their NHI data to third parties. The opt-out request was denied by the NHIA and a 10-year lawsuit from the individuals and NGO against the NHIA then began [4]. The plaintiffs argued that they had not granted their NHIA permission for any secondary uses of their NHI data. In addition, based on Taiwan Constitutional Law [5] and Personal Data Protection Act of 2012 (PDPA) [6], they had information privacy right to "opt-out" from the "unauthorized secondary uses".

The main counter-arguments from the defendant, NHIA, were that, firstly, all NHI data sharing with third parties were appropriately encrypted and de-identified, and therefore, there is no concern for data privacy or security. According to Article

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6 of the PDPA, personal [health] data can be processed and used without data subjects' consents, as long as it is for "*statistics gathering or academic research by a government agency or an academic institution for the purpose of healthcare, public health, or crime prevention"* and "*such data, as processed by the data provider or as disclosed by the data collector, may not lead to the identification of a specific data subject*" [6].

NHIA also alleged that, the whole society benefits from the academic research based on using NHID, and the plaintiffs' information privacy right could still be limited under certain circumstances. This was the case that the public interests of academic research and medical development shall trump the plaintiffs' information privacy.

Courts, both lower and appellate levels, essentially supported the NHIA's arguments, and ruled in favor of the government agency. The plaintiffs then had the opportunity to appeal the decision in 2017 before the Taiwan Constitutional Court to challenge the ruling.

III. TAIWAN CONSTITUTIONAL COURT DECISION: 113-HSIEN-PAN-TZI NO.13 JUDGMENT

On August 12, 2022, the Taiwan Constitutional Court held a press conference to announce their decision of the NHID case, the 113-Hsien-Pan-Tzi No.13 Judgment [7]. In this final and landmark verdict, the Grand Justices reversed the earlier judgements from the lower courts, and reaffirmed that the information privacy right under Taiwan Constitution shall include both procedural aspects, like an independent supervisory mechanism, as well as substantial aspects, such as a right to opt-out (The holdings of the Judgement, See Table 1).

TABLE I. THE ISSUES AND HOLDINGS OF THE JUDGEMENT [7]

Issues	**The Court's Holdings and Prevailing Parties**		
	Court holdings	***Petit.***	***Resp.***
Whether the Article 6 of the PDPA is unconstitutional?	No.		V
Whether the current PDPA has no independent supervisory mechanism is unconstitutional?	Yes. Competent Authority is obligated to amend the law within 3 years.	V	
Whether the current rules of NHID's data utilization is unconstitutional?	Yes. Competent Authority is obligated to amend the law within 3 years.	V	
Whether the current practice that people can not opt-out from secondary uses is unconstitutional?	Yes. Competent Authority is obligated to amend the law within 3 years. Otherwise, people can enforce the right directly.	V	

Several impacts on Taiwan's health data use have emerged immediately after the judgment rendered:

Firstly, it is the first time in Taiwan's legal history that the General Data Protection Regulation (GDPR) of the European Union (ER) is cited as a good comparative law model for setting up a data protection supervisory body. In the ruling, the Grant Justices have imposed the obligation to the competent authority for amending the laws within three years. Apparently, the EU GDPR model will be the must-seen reference for Taiwan's legislators.

Furthermore, what constitutes a sufficient "de-identification obligation and process" becomes a hot issue again. Under the Enforcement Rules of the PDPA, the definition of de-identification means "inability to identify specific individuals by coding, anonymizing, and hiding part of personal data or by other means". However, no one really knows what it is. A set of more precise and practical protocols of de-identification, such as the pseudonymization under the EU GDPR or the safe harbor method under the US Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule, shall be created.

Finally, the judgment affirmed the right to opt-out for unwilling or unauthorized secondary use of the data. Before the ruling, it was unclear whether the information privacy right under Taiwan Constitution law and judicial interpretations could extend to ex-post determination of personal data control. It is now clear, nevertheless, that the data subject has the final call for its data, not the government. In other words, even though the data is collected, processed, and used by the government, it is the people have the ultimate control over their data.

IV. CONCLUSION: WHAT NEXT STEPS ARE?

While Taiwanese government, in particular the NHIA, has learned its lesson about information privacy and health data governance through the case and the ruling, their impacts are likely beyond the jurisdiction.

On the one hand, the Taiwan Grand Justices have pointed out, in the ruling, that the EU GDPR model shall be a reference for NHIA to amend current regulations and practices. Some Taiwanese privacy scholars have also proposed comparative law examples for Taiwan's data governance reform, such as the England model under the Health and Social Care Act of 2012 [8], or a trustworthy data governance mechanism for developing a better framework [9].

The decision and its further development, on the other hand, may also be a good reference for secondary use of health databases from around the world, such as MyData in the South Korea or Findata in Finland [10][11].

As health data's huge potential is emerging every minute, how to build up a constitutional and more trustworthy regime of health data governance, becomes critical and urgent worldwide.

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Co-designing Assistive Technology with and for Persons Living with Dementia

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***Abstract*: Dementia is a chronic and progressive neurodegenerative illness, which can lead to significant difficulties in a person's capacity to perform activities of daily living (ADLs) and engage in meaningful activities. There is an acute need, which digital health technologies can potentially fulfil, to provide proactive support for persons living with dementia (PLwD) and their caregivers. However, there is limited involvement of PLwD in the design of technology that could be used to support their personal plans for independent living at home. In this paper, we describe how we are employing a co-design methodology to support engagement in an assistive technology toolkit for managing ADLs for people living with the early stages of dementia.**

Keywords-co-design; assistive technology; dementia.

I. INTRODUCTION

It is estimated that close to 50 million people globally are living with dementia and that each year there are 9.9 million new cases of dementia worldwide [1]. According to research carried out by the Alzheimer Society of Ireland (ASI), an estimated 64,000 people are living with dementia in Ireland [2]. Increasing age remains the strongest risk factor for dementia, with prevalence rates nearly doubling every five years over the age of 65. With an aging population, the number of people with the condition will more than double in the next 25 years to over 150,000 by 2045, representing 2.5% of the Irish population [2]. PLwD have higher utilization of healthcare services and higher healthcare costs than those without dementia [3]. From a carer perspective, half a million people in Ireland have a family member with dementia. The care burden associated with dementia is significant and a recent meta-analysis found dementia family caregivers to be significantly more stressed than non-dementia caregivers and to suffer more serious depressive symptoms and physical problems [4]. The Irish Health Service Executive and ASI advocate that people with dementia who want to remain in their own homes should be supported to do so for as long as possible with high quality home care services.

There is an acute need, which digital health solutions can potentially fulfil, to provide proactive support for PLwD and their caregivers. However, there is limited involvement of people with dementia in the design of technology that could be used to support their personal plans for independent living. The majority of dementia technology is focused on monitoring, security and safety [5]-[7]. The primary user of these types of technologies is typically the carer, while the PLwD is often a passive user.

Our research aims to bring together a multidisciplinary team to co-design new assistive technologies with and for PLwD. Specifically, we are focused on developing a digital toolkit to support someone living with mild-to-moderate dementia, together with their informal carer(s) to plan and monitor personalized care goals, with targets derived from care plans, existing models of daily activities, as well as activities described as meaningful by the individual PLwDs and their carers. The toolkit will include a visual application for tasks, such as setting up care plans and goals for ADLs. This paper discusses the importance of co-design methods to support PLWDs' engagement in the design of technology to support their care.

II. BACKGROUND

A. *Quality of Life (QoL)*

Lawton's model of QoL [8] has been highly influential in QoL and dementia research and has driven the approach to and development of QoL instruments. This model suggests assessment should involve both subjective and objective factors and it identifies four main dimensions that contribute to QoL: psychological well-being, behavioral competence, objective environment and perceived QoL.

B. Activities of Daily Living (ADLs)

Independent living tasks can be categorised into ADLs, which concern basic activities relating to personal care and hygiene, as well as Instrumental Activities of Daily Living (IADLs) which are more complex and concern activities needed to function and reside independently in the community [9]. IADLs can be categorised as follows: transportation shopping, finances, meal preparation, housekeeping, managing communication and medications.

C. Meaningful Activities

Both PLwDs and their carers have reported that daytime activities, social contact, as well as issues relating to psychological distress comprise the areas of life which are most negatively affected by dementia. To design programs which both satisfy psychosocial needs and improve QoL for PLwD, it is therefore crucial to establish what their views and experiences are regarding meaningful activities. The

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sense of meaning attached to these activities comes from a sense of pleasure, connection, participation or autonomy. These feelings are apparent and relevant regardless of cognition and dependency levels [10].

III. METHODS

A. Recruting Participants

We aimed to recruit individuals with a diagnosis of Mild Cognitive Impairment (MCI) or early-stage dementia. Participants were recruited through two sources: the ASI or through a local outpatient referral centre for older adults. Recruited Occupational Therapists (OTs) all worked at the same outpatient referral centre, which specializes in assessing and managing cognitive impairments, most common types of dementia, frailty syndromes, as well as a variety of other diseases associated with ageing. Information leaflets describing the study were provided and clinicians made the first approach to potential participants. The aims, procedures, risks, and benefits were outlined, and the clinicians provided an overview of the study. Participants needed to be able to understand the study requirements and give informed consent. We recruited five PLwD and five of their informal carers, as well as five healthcare professionals Prior to the study, ethical approval was received from the university and health service research ethics committees.

B. Data Collection

Participants initially took part in interviews or focus groups to explore requirements in detail. Following a review of the literature, data was collected from participants about the following topics - what constitutes QoL for them, how to maintain QoL, the relationship between engaging in daily activities and maintaining QoL, and which activities bring meaning and why. Participants' discussed how technology could support them in engaging in and maintaining ADLs for better QoL. Interviews and focus groups with healthcare professionals provided a clinical perspective of what is important for self-care and care planning for PLwDs and their carers and how technology can support self-care and care planning for dementia. PLwD and informal carer participants also took part in a series of four co-design workshops to co-design the toolkit. Interviews and focus groups were conducted face-to-face in individual participant's homes as well as online due to Covid-19 restrictions. Participants had the option to participate in the interview with their informal carers and four out of five participants opted to do this. Sessions were audio recorded using Zoom or using a dictaphone for face-to-face sessions. Co-design workshops took place in a research centre and involved all of the PLwD and informal carer participants together.

C. Data Anaylsis

Analysis is currently ongoing. Transcripts are being thematically analyzed in NVivo (qualitative data analysis software) following the six-step approach outlined in Braun and Clarke [11], to provide a framework for identifying the themes or patterns within the data.

IV. DISCUSSION

Technologies for self-management for PLwD need to consider not only compensation for deficits, but also ways in which positive and meaningful experiences can be highlighted and encouraged We are developing an assistive technology toolkit for PLwD for maintaining ADLs and meaningful activities. The toolkit will be evaluated in a field trial later this year and a series of questionnaires, including CASP19 for QoL [12], will be used to evaluate effectiveness of the toolkit for managing ADLs for PLwD.

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Electronic Health Records User Satisfaction:

Experience after implementation of a new system in Northern Norway

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***Abstract*—The study assessed user satisfaction with a new Electronic Health Record (EHR) system in the Northern Norway Regional Health Authority and compared it to a baseline. The baseline surveys were conducted in 2016 and 2018, and the survey after implementing the new HER system was done in 2021. A comparative analysis was performed, with the primary statistical method used for analysis being frequency (percentage) for discrete variables and mean for continuous variables. The one-way analysis of variance (ANOVA) was used to determine whether there are any statistically significant differences between the means of satisfaction for baseline data vs. the 2021 data. The results indicated an improvement in overall user satisfaction with the new system, with many users being either satisfied or neutral. The study also analyzed the generic satisfaction factors of the EHR system and found a positive shift from dissatisfaction to satisfaction or neutrality. The study revealed that specific functions of the EHR system still require improvement, with the lowest satisfaction ratings given to overview of drug treatment, prescribe drugs, and care planning. However, users were most satisfied with the functions of the overview of outstanding tasks and the overview of patient issues. The results also showed a reduction in system interruptions compared to the baseline, contributing to higher user satisfaction. Overall, the results suggest that the new EHR system has improved user satisfaction compared to the previous system, but further improvements are needed for enhanced user experience. Increased user satisfaction is an important finding considering theory of the installed base that states an expected decrease in satisfaction when implementing a new system.**

Keywords-Electronic Health Record (EHR); Usability; User Satisfaction; Computerized Clinical Decision Support Systems (CCDSS); Installed Base.

I. INTRODUCTION

The focus has been directed toward digitalization in an effort for more efficient ways to operate the healthcare system. Part of the digitalization process has been the increased adoption of Electronic Health Records (EHR) [1]. In the last twenty years, the rapid development of EHR systems has changed what is possible to do within an EHR system. The development has gone from merely creating and storing the patient's health records electronically to an integrated health information system that helps patients and healthcare workers in their daily life, with examples such as clinical decision support [2][3].

The Norwegian government has long been pushing for a new generation of EHR systems, mandated by the national white paper 9, 'One citizen – one Health Record [4]. Thus, in the last decade, there has been a planning process for considerable change in the EHR infrastructure in Norway. Three of four regional health authorities used the EHR system DIPS Classic, and the fourth region used DocuLive EHR. Norway's four regional health regions started implementing new EHR systems in 2021, which is still ongoing. DIPS Classic will be replaced with DIPS Arena, and DocuLive will be replaced with EPIC EHR. The first health region to implement DIPS Arena was the Northern Norway Regional Health Authority. DIPS Arena is a Norwegian-developed EHR built on an Open EHR platform, their third-generation journal system. The new system is expected to provide new possibilities while ensuring patient safety according to international standards and providing a modern user interface.

While there are mixed results, some research says that the EHR is suggested to improve the efficiency, quality of care, and create a better workflow [1]. It also might have some negative consequences, such as more time-consuming documentation [5] practices and increased burnout [6]. In addition to the usual undesirable aspects of EHR, implementing a new EHR system adds further obstacles, with barriers such as a lack of training and support, restrictions on resources, and a lack of literacy [1]. Prior research has shown that an EHR implementation going from one EHR system to another is difficult to accomplish [7]. The basic principle of an Information Infrastructure (II) is that it is never built from scratch; instead, it grows through the evolution of an installed base [8]. The Installed base grows and increasingly influences its environment during its revolution from being implemented to being replaced [7]. The evolution of an implementation process where generic systems replace essential parts of an II increases the risk of failure and unexpected side effects. Due to this, an implementation should build on the installed base instead of replacing it to succeed [9]-[11]. To optimize the utilization of the EHR system and further improvement, an in-depth understanding of user satisfaction is necessary. User satisfaction can be influenced by a multitude of factors [12], including but not limited to usability [13] and prior system experience [14].

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Previous studies have looked at measuring user satisfaction [15] and functionality [16] with the EHR systems in Norway. This study seeks to examine if this trend continues with the implementation of a new EHR system, as we were able to measure user experience shortly after the implementation. Thus, this study aims to evaluate user satisfaction in the implementation phase of the new EHR system and compare it with user satisfaction from the former EHR system to see if there is any change in satisfaction.

This paper's overall structure contains five sections: Section II explains the applied quantitative methods. Section III presents the study's results on satisfaction and discusses ethical considerations and limitations. In Section IV, we discuss comparing the data and the findings. In the last part, Section V, we conclude with the results and suggest how to increase satisfaction for suppliers, health workers, and policymakers.

II. METHODS

In this section, we focus on the questionnaire, statistical methods, and data collection.

A. Setting

Norway's four regional health authorities govern the hospital sector: SouthEast, West, Central, and North. All the regions were in the year 2021 in a transition phase, preparing to implement a new EHR system. Northern Norway Regional Health Authority hospitals transitioned from DIPS Classic to DIPS Arena in 2021. Region West was the next to implement the same system in 2022. Region SouthEast has decided to implement the new system by 2025. The Central Region started a transition from DocuLive EHR to EPIC EHR system in 2022. This process is ongoing, and some hospitals still use the old system. All the regions are transitioning from an already existing electronic health record.

This paper will compare data before and after implementing the new EHR system in the Northern Norway Regional Health Authority. The data collection was done in 2021 as they were the first and only region to start implementing the new system. The hospitals include the University Hospital of North Norway (UNN), Nordland Hospital (NLSH), and Finnmark Hospital (FSH).

B. Data collection

This paper makes use of three surveys among EHR users in Norwegian hospitals. The first survey from 2016 included physicians only [12]. The EHR system in use was DIPS Classic. A total of 402 physicians were enrolled from three Norwegian hospitals, and 208 physicians (52%) submitted a fully answered questionnaire. Data from the largest hospital (Oslo university hospital) was included in this study. Exclusion criteria were no patient contact or if they had been employed for less than three months. Up to 10 reminders were sent in case of no response.

The second survey was administered in the autumn of 2018 [11]. The hospitals contributed with employers' email addresses, and a random-number generator selected the participants. EHR systems in use were DocuLive and DIPS Classic. For this survey, both physicians and nurses were included. A total of 506 clinicians were invited for the survey. You had to work full-time at one of the included hospitals to be included. A total of 299 persons completed the questionnaire, where 60 (20.1%) had a profession as nurses, and 239 (79.9%) were physicians. Response rates were 35.0%, 22.0%, and 29.0% for physicians, nurses, and all clinicians. Ten reminders were issued between September to December 2018.

The latest and present survey was conducted in the autumn of 2021 after implementing the new EHR system. The hospitals wanted to administer the participant recruitment themselves. The invitation was sent to all hospital employees. The EHR system in use was the new DIPS Arena. A total of 603 employees started the survey, and 221 (36.5%) completed the survey. These respondents were EHR users of different professions. Physicians, nurses, and other professionals accounted for 25.8%, 36.2%, and 38.0%, respectively. The three hospitals had 5,393 full-time equivalent positions in 2021, of which 1,606 (30.0%) were doctors, and 3,787 (70%) were nurses. The studied population of doctors and nurses represented 2.5% of the total number of full-time equivalent positions, with 3.6% of all doctors and 2.1% of all nurses. The sampling method is not ideal due to the lack of control over who got the survey. This may have affected which groups answered the survey, and it may lead to a bias where those who are more interested in the topic or have a stronger opinion may be more likely to respond. In this data collection, the hospital administration issued two reminders to the respondents from September to December 2021.

As data included in this paper regards hospitals using DIPS Classic (2016 and 2018 surveys) and DIPS Arena (2021 survey), this excludes one hospital from the 2018 survey as they used another EHR system (DocuLive EPR). From the 2021 survey, only nurses and physicians were included in the data analysis to compare the clinical roles from the 2016 and 2018 data collection. In this sense, survey data from 2016 and 2018 serves as a baseline compared to the results after implementing the new DIPS Arena in 2021.

C. Questionnaire

The survey is based on a previously validated questionnaire [17]. Changes were made in 2021 to the full questionnaire as it was too time-consuming. However, the items regarding satisfaction remain equal to the previous studies. This new questionnaire is an early effort to develop ISO-based indicators for user satisfaction among clinical EHR users.

TABLE I. DATASET, BASELINE AND 2021 DATA

Health Region (Survey year)	Clinical profession		
	Physicians, n	*Nurses, n*	*Total, n (%)*
West (2018)	34	12	46 (12.3%)
South-East (2016)	152	0	152 (40.7%)
North (2018)	22	17	39 (10.4%)
North (2021)	57	80	137 (36.6%)
Total	265 (70.9%)	109 (29.1%)	374 (100.0%)

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Two different survey programs were used to conduct the survey: in 2018, Questback (Questback, Oslo, Norway), and in 2016 and 2021, Limesurvey (LimeSurvey GmbH, Hamburg, Germany). All questionnaires were anonymous and constructed dynamically, hence that the respondents would only answer relevant questions that were relevant to them. Before conducting the surveys, they were piloted through interviews to get the necessary feedback.

The questionnaire mainly used a 5-point Likert scale ('Completely disagree,' 'Partially disagree,' 'Neutral,' 'Partially agree, 'Completely agree'). Some questions were only rated as agree/disagree or asking for a numeric response. Three sub-categories are used to measure user satisfaction; EHR Function satisfaction (11 items; Q1-Q11), EHR Generic satisfaction (four items; G1-G4), and EHR Overall satisfaction (one item; O1).

D. Analysis/statistical methods

The main statistical methods used for analysis were frequency (percentage) for discrete variables and mean for continuous variables. The one-way analysis of variance (ANOVA) was used to determine whether there are any statistically significant differences between the means of satisfaction for baseline data vs. the 2021 data. The significance level was considered p=.05. The statistical software SPSS 25 (IBM Corp., Armond, NY) was used for the analysis. In the process of cleaning data, we had to address missing values. There was a high number of missing values for satisfaction items, n=616 (24.4%), as some questionnaire items depended on profession (e.g., nurse do not prescribe drugs). Several imputation techniques have been suggested when missingness is completely random (MCAR) and when there are no systematic reasons for missingness [18]. We addressed missing values by applying the MCAR assumption by Little [19]. The results confirmed that the missingness is MCAR ($\chi 2$ =1564.299, df=1493, p=.10). Then, we let SPSS impute our missing values based on the expectation-maximization (EM) analysis that estimates the means, correlations, and covariances.

E. Ethics

The Regional Committee for Medical and Health Research Ethics South-East Norway has been consulted. According to national regulations and ethics, approval was not required because the study did not involve biomedical research, and all data were anonymized.

III. RESULTS

A. Baseline data

The number of participants that completed the 2021 questionnaire and were EHR users was n=221 (82.5%). From this sample, 70.1% were female; the mean experience was 17.4 years (*sd*=11.0); the mean age was 45.9 years (*sd*=11.6). The clinical field with the highest number of participants was the aggregation of those treating conditions related to mental health and substance abuse (30.8%), medical (29.4%), surgical (19.0%), and other (20.8%). Physicians, nurses, and other professionals accounted for 25.8% (*n*=57), 36.2% (*n*=80), and 38.0% (*n*=84), respectively. Participants from the hospitals, FSH, NLSH, and UNN accounted for 28.5% (n=63), 40.7% (n=90), and 30.8% (n=68), respectively.

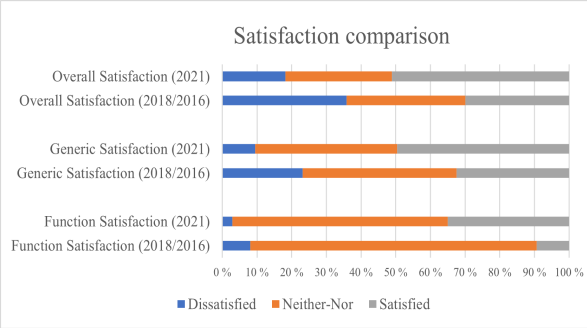

Figure 1. Comparison between changes in satisfaction for the three types of satisfaction.

Table I summarizes the baseline data by year, health region, and participants' clinical role. The clinical field with the highest number of participants was the aggregation of those treating conditions related to mental health and substance abuse (30.8%), medical (29.4%), surgical (19.0%), and other (20.8%). Physicians, nurses, and other professionals accounted for 25.8% (*n*=57), 36.2% (*n*=80), and 38.0% (*n*=84), respectively. Participants from the hospitals, FSH, NLSH, and UNN accounted for 28.5% (*n*=63), 40.7% (*n*=90), and 30.8% (*n*=68), respectively.

Table I summarizes the baseline data by year, health region, and participants' clinical role. The clinical field with the highest number of participants was the aggregation of those working in the medical field, with n=169 (45.2%). The following fields with the highest number of participants were

TABLE II. ANOVA RESULTS FOR SATISFACTION ITEMS

Satisfaction items	ANOVA		
	F	*df*[a]	*p*
Q1 Read medical reports	70.439	1	.000[b]
Q2 Compare treatment and efficacy	9.351	1	.002[b]
Q3 Overview patient issues	22.071	1	.000
Q4 Read radiology reports			n.s.
Q5 Overview outstanding tasks	11.935	1	.001
Q6 Communicate with patients	33.099	1	.000
Q7 Advise further treatment	56.128	1	.000
Q8 Prescribe drugs	142.034	1	.000
Q9 Plan for treatment and care	271.343	1	.000
Q10 Assess right to priority health care	20.962	1	.000
Q11 Overview drug treatment	24.929	1	.000[b]
G1 Effective patient work	7.306	1	.007
G2 EHR Quality	23.021	1	.000
G3 Worth effort	5.865	1	.016
G4 User friendly	18.017	1	.000
O1 Overall Satisfaction	21.037	1	.000

a.df within groups = 372. b. 2021 satisfaction is lower than baseline.

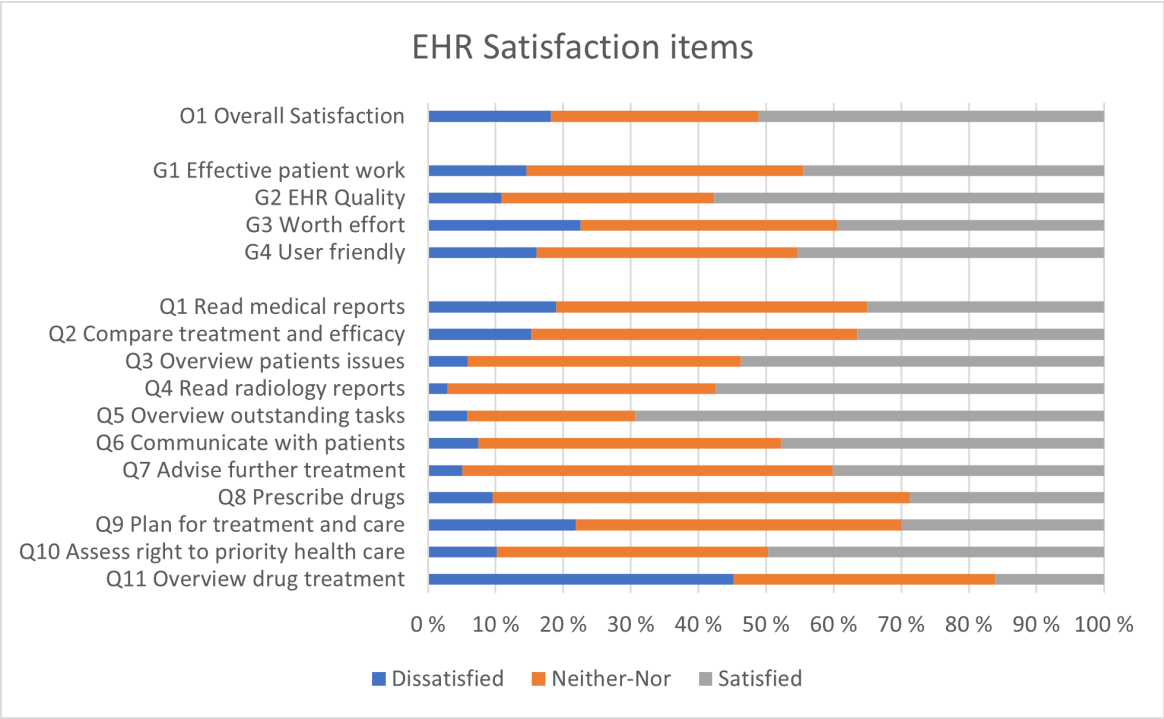

Figure 2. The satisfaction items with response categories

related to surgical, psychiatry, and others, with n=130 (34.8%), n=36 (9.6%), and n=39 (10.4%), respectively.

B. Questionnaire results and interuptions

Two questions related to interruptions of the clinical workflow while using the EHR. The first one regarded interruption caused by login requests; results range from 4 to 50 interruptions per day (outliers removed). The mean number of interruptions for physicians and nurses per day is 15.13. The corresponding number from the 2018 and 2016 data was 17.21 and 17.15, respectively.

The second interruption regarded interruption due to the EHR hanging or crashing. The median number of interruptions is four, corresponding to one per month in the scale used. The corresponding numbers from the 2018 and 2016 data were three, once a week, for both studies. Only 12.3% of respondents reported interruptions that occurred once or more per day, 36.1% reported weekly interruptions, and 51.5% reported interruptions that ranged between once a month and none. The corresponding numbers from the baseline data were 35.1%, 37.7%, and 27.3%, respectively.

C. User satisfaction

The aggregated results for the three types of satisfaction significantly increased after the implementation of the new system, see Figure 1. There was a statistically significant effect on the satisfaction from the 2021 survey, except for item Q4 (See Table II). Items Q1, Q2, and Q11 show a significant decrease in satisfaction. An overview of the single items for satisfaction is in Figure 2.

EHR Function satisfaction. For overall function satisfaction (questiQ1-Q11), 35.0% of respondents reported being satisfied, 30.7% neither satisfied nor dissatisfied, and 18.2% dissatisfied.

The highest satisfaction was reported for Q5 (overview of outstanding tasks), where 69.3% of respondents were satisfied. This item has the lowest indifferent rating, 24.8%, and the third lowest dissatisfaction rating, 5.8%. In addition, functions for Q5, Q3 (overview patients' issues), and Q4 (read radiology reports) all have high satisfaction rates, all above 50%. For Q4, there is no significant change from the baseline measurements.

The lowest satisfaction was measured for Q11 (overview drug treatment); only 16.1% of the respondents were satisfied. Compared with baseline data, this function has a significant decrease in satisfaction. At the same time, this function has the highest dissatisfaction rating, 45.3%. Less than 30.0% were satisfied with the functions for Q11, Q8 (prescribe drugs), and Q9 (plan for treatment and care).

The function with the highest indifferent rate was Q8, 61.8%. This function scores low both on satisfaction (9.6%) and dissatisfaction (28.7%).

Three of the functions score are in the mid-range for satisfaction, Q6 (communicate with patients), Q7 (advise further treatment), and Q10 (assess right to priority health care), with satisfaction scores in the range of 40.1% to 49.6%. These items also have a low dissatisfaction score (7.5%, 5.1%, and 10.2%, respectively) and indifferent scores in the mid-range (44.8%, 54.7%, and 40.1%, respectively).

Items Q1 (Read medical reports), Q2 (Compare treatment and efficacy), and Q11 show a significant decrease in satisfaction. No significant differences were found in EHR Function satisfaction among hospitals or user categories.

EHR Generic satisfaction. Generic satisfaction refers to effectiveness, high quality, the worth of time and effort, and user-friendliness; overall, 49.6% of respondents were

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satisfied; 40.9% were neither satisfied nor dissatisfied; 9.5% reported being dissatisfied.

Generic satisfaction for Quality (G2) was reported as high by 57.7%. The other factors have reasonable satisfaction rates, between 39.4% and 45.3%. The dissatisfaction is highest for Worth the Effort (G3), with 21.3%, while the other items have dissatisfaction rates between 10.9% and 16.1%. All four generic items have a significantly higher satisfaction rate in the 2021 survey vs. baseline. No significant differences were found in EHR Generic satisfaction among hospitals or user categories.

EHR Overall satisfaction. A single item assessed overall satisfaction, where 51.1% of respondents were satisfied, 30.7% were neither satisfied nor dissatisfied, and 18.2% reported being dissatisfied. The general satisfaction item has a significantly higher satisfaction rate in the 2021 survey vs. baseline. No significant differences were found in EHR Overall satisfaction among hospitals or user categories.

IV. DISCUSSION

The study evaluated user satisfaction with a new EHR system in hospitals in Northern Norway health authorities and compared it with a baseline based on the old system. The results indicated that many users were either satisfied or neutral. Compared to data from the baseline, a significant improvement in user satisfaction was observed in the present study. One explanation for this change can be that the previous system was not perceived as good enough and that the difference (e.g., user interface) was enough to improve users' satisfaction. On the other hand, it can be interpreted that the implementation of the new EHR system was well-planned, the process was incremental and that the user was given enough training on the new system, hence overcoming a usual barrier of implementing a new EHR [1].

Generic satisfaction (effectiveness, high quality, the worth of time and effort, and user-friendliness) looks further into some core aspects of usefulness that contribute to the satisfaction of the system. The results revealed a positive and significant change in generic satisfaction, with a decrease in overall dissatisfied users. This study found that the percentage of users dissatisfied with the system at the baseline has changed positively, shifting from dissatisfaction to either satisfaction or neutrality. Quality (G2) had the highest reported number of satisfactions, but it also included Worth the time effort (G3), which had the highest number of reported dissatisfactions. An interpretation of this development is that the vendor and the user had experience with the previous EHR system, DIPS Classic, which could have contributed to an easier transition when implementing DIPS Arena.

When analyzing specific functions of the EHR system, overall improvements in functional satisfaction were observed, but some functions still required improvement. The functionality related to overview of drug treatment (Q11), prescribe drugs (Q8), and care planning (Q9) received the lowest satisfaction ratings. The exact reason why these functions received low satisfaction is not apparent in the data. Still, these are central features of the clinical work, and the low satisfaction rating raises concerns for the vendor. However, these are complex features that several actors are trying to solve, including the government (Shared Digital Medication List). Overview of outstanding tasks (Q5), an overview of the patient's issues (Q3), and read radiology reports (Q4) were the functionality with the highest user satisfaction. This finding can be interpreted as the vendors having enhanced the new system's design, making it more user-friendly and efficient.

Also, the data showed a reduction in the frequency of system interruptions, such as crashes or hangs, compared to the baseline data. This finding can be interpreted that vendors have simplified and stabilized the new system. This improvement can contribute to higher satisfaction among users.

The results of this study suggest that the new EHR system has been well-received by users and has improved user satisfaction compared to the previous system. The notion of Information Infrastructure and the concept of the installed base is confirmed in our results [9]-[11]. The approach of the change between EHR systems where parts of the installed base have been kept can explain the implementation success. The socio-technical ensemble of systems is kept among the users, same system vendor, and slow incremental implementation process where structure data elements are the next implementation step. A further follow-up will be necessary for a prolonged conclusion. However, certain functions still need further improvements to enhance the overall user experience. The findings in this study will support the work regarding developing standardized indicators for usability in general and user satisfaction in particular.

V. CONCLUSION

In conclusion, the study aimed to assess user satisfaction with a new EHR system in Northern Health Authorities and compared it to a baseline. The results showed that many users were either satisfied or neutral, indicating a significant improvement in user satisfaction compared to the baseline data. An analysis of generic satisfaction showed positive changes in the system's effectiveness, quality, the worth of time and effort, and user-friendliness, with a decrease in overall dissatisfied users. Although specific functions still require improvement, the new EHR system has been well-received by users. It has improved the overall user experience, which is significant considering the many known barriers when implanting a new EHR building on the theoretical concepts of an Information Infrastructure and the installed base. Further research should continue monitoring user satisfaction and consider complementing quantitative findings with qualitative research for in-depth knowledge of why user reports are satisfied.

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Valkyrie:
A Distributed Service-Oriented Architecture for Coordinated Healthcare Services

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Abstract— **The Valkyrie project aims to address the increasing number of individuals struggling with mental disorders in Norway and the pressure this has placed on the healthcare system. The project focuses on the coordination of services and the need for information across clinical levels in the healthcare system. Valkyrie aims to provide access to quality care and reduce the adverse effects of mental disorders. The Valkyrie project will contribute to the United Nation sustainable development goals and enhance healthcare services in Norway by facilitating knowledge transfer, improving interaction across care settings, and providing new knowledge on digitalization and patient-centric care. The project aligns with the National e-Health Strategy and supports several priority areas of the e-Health Plan.**

Keywords-Electronic Health Records; Voice of the Patient (VoP); Coordination; Healthcare; Patient-centric Pathways; Service-Oriented Architecture (SOA); Virtual Health Record.

I. INTRODUCTION

The full coordination of health care services entails that the correct data is available to the right person at the right time, regardless of where the patient has previously received medical care. This concept is a critical objective in the Norwegian national strategy of "One citizen – One Journal" [1]. From an Information and Communication Technology (ICT) standpoint, this means connecting multiple Healthcare Information Systems (HIS) across multiple healthcare levels. The Valkyrie project responds to the challenge and will demonstrate its feasibility by making a technological prototype.

A prominent example of a target group in contact with multiple healthcare providers across the Norwegian healthcare system to complete their care plan is persons with mental disorders. The common use that a person with mental disorders makes of the Norwegian healthcare system is hospitalization, outpatient, and day services in specialist healthcare, as well as GP, emergency-, care-, social-, rehabilitation-, and day services from the municipality. In the current scenario, GPs do not have access to electronic Patient Health Data (ePHD) from the municipality services or specialist care. Only standardized documents are exchanged, which is insufficient for health professionals responsible for the patient. A WHO report revealed that persons with mental disorders in Nordic countries have a two- to three-times higher mortality rate [2]. The risk factors for this excessive mortality strongly relate to the service delivery, particularly regarding the lack of coordination and management of the health care services as the main contributors [2]. Furthermore, medical comorbidity is expected in this target group [3], where the majority suffers from at least one chronic medical condition requiring somatic care [4] in addition to their mental care. This target group´s demand for Norwegian healthcare, makes it an excellent case study for Valkyrie.

Norwegian Directorate of Health National Plan for Implementation of Patient Pathways [5] has identified challenges with the digitalization of the Norwegian healthcare sector, recognizing the need for more research to better use of ePHD. A need has also been identified for implementing new patient pathways for mental health, which improve the coordination between primary and specialist care [5][6]. However, the challenges of accessing ePHD across multiple HIS, and integrating it with patient-centric solutions to form complete pathways, threaten the chances of achieving the goals for patient pathways. We should clarify that the use of data from the patients' journals to support patient pathways is provided by the Norwegian Patient Journal Law Chapter 2 (§§7-10, 19) [7], as well as on the Patient Records Act and the Health Register Act [8] that explicitly points out that business boundaries should not hinder the sharing of health information.

It is of significant relevance for the "digital interfaces, robotics, and virtual environments" research area to establish an open and standard methodology to describe patient-centric pathways with a high level of granularity in a form that allows ePHD to become ubiquitous by being made available in multiple HIS across multiple settings. Thus, establishing the foundations for health care services coordination.

Valkyrie will model patient-centric pathways that guide a Virtual Health Record (VHR) outline. The VHR will be made available to the providers' HIS, thus making it possible to, when relevant, access a view of ePHD. Hence, all ePHD will

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become ubiquitous in facilitating health care services coordination. This paper will define the process of how to solve this in a real-life setting.

This paper is structured in five sections. Section one, this section, presents the introduction of the paper. In section two we present the state of the art, followed by a presentation of the Valkyrie solution in section three. Section four presents the discussion, and we end the paper with a conclusion in section five.

II. STATE OF THE ART

Research has shown benefits for patient-centric care, such as improved quality of life, increased adherence to treatment protocols, and reduced morbidity [9]. On the other hand, the current HIS are not designed to support integrated care delivery that spans multiple providers and settings at any health care level. ICT is set to play a significant role in coordinating healthcare providers who are often separated by time and space. However, introducing ICT into healthcare has proven challenging owing to the underlying complexity of healthcare processes and the number of actors involved in those processes [10].

A. Modelling patient-centric pathways

According to the Norwegian Directorate of Health [6], a pathway is a national standardized patient pathway with the aim to contribute to rapid diagnosis and treatment initiation without unnecessary waiting time. A patient-centric pathway is a structured care plan that combines national guidelines with local practices and patients' wants, needs, and preferences.

Healthcare delivery can be represented as a continuum that moves from the micro-level to the macro-level [12]. The macro-level represents system-level processes, such as patient flows through a hospital, while the micro-level represents processes at the individual patient care level. Although they are interrelated, the micro- and macro-levels require different modeling approaches owing to their different granularity levels.

Business process modeling has been used in healthcare to help represent healthcare processes so we can design systems to support those processes. Jun et al. [13] point out that a better application of process modeling is needed to provide safe, effective, timely, and patient-centric healthcare services. Process modeling (particularly simulation models) has helped evaluating and understanding healthcare processes at the macro-level by developing models such as those proposed by Granja et al. [14] for resource usage and radiology flows. However, micro-level modeling at the patient's level is far less advanced. Micro-level models require explicit details about the ePHD and communication flows across processes and healthcare providers. An example of micro-level modeling is the work of Malholtra et al. [15], who developed a comprehensive model of the providers, activities, and ePHD flows in the intensive care unit to identify, characterize, and reduce medical errors in that unit. Nevertheless, one shortcoming with their work is that it was ad hoc and did not use a formal modeling language or methodology, not easing the identification of specific indicators or best practices that can be considered for implementing such models and ensuring their scalability to other health domains.

B. Distributed Service-Oriented Architecture

When redesigning a healthcare system and design ICT to support it, we need to move from delivering individual products to delivering integrated services [11]. From the perspective of healthcare ICT, this means moving away from developing ICT for separate tasks (e.g., decision support, order entry) to developing integrated HIS that supports the continuity of healthcare delivery over time. The Service-Oriented Architecture (SOA) paradigm and its ability to connect multiple HIS across different settings is a candidate for developing integrated HIS to support healthcare services coordination across different settings. SOA was introduced in healthcare to help break down silos and monoliths by separating the interface and services from the content and business logic and exposing it as a chain of interrelated services, feeding into expectations of better communication and interoperability between healthcare organizations and patients.

The adoption of SOA and its healthcare principles is still slow when compared to other industries [12]. The reasons for this are linked to the also slow adoption of common standards and that SOA introduces a new type of complexity – if one service goes down, the whole chain of services breaks – which has led to more point-to-point integrations instead of using a separate process layer (e.g., enterprise service bus). Interoperability is still an issue, especially semantic interoperability [13], i.e., how to deliver the meaning and context together with the ePHD seamlessly across HIS [14]. More recently, an adaption of SOA has emerged, known as the Microservices architecture [15]. SOA and the Microservices architecture share the same ideas on exposing business processes as services. However, opposite to SOA, the Microservices architecture divides a monolithic application into multiple atomic services that run independently on distributed computing platforms, including distributed data stores.

C. Mental health as a case-study

In Norway, the yearly prevalence of mental illness ranges between 16 and 22% of the population [16]. Although most of these persons have not been in contact with the healthcare services [17], approximately 12.5% of the adult Norwegian population has a consultation in primary care related to psychological ailments, being that for specialist healthcare, the number of consultations is at 15% [16]. The fragmented organization of the health and social welfare services in Norway constitutes a major barrier to providing comprehensive, integrated, and coordinated services for persons in the target group.

Since 1999, the Norwegian healthcare sector has been through several reforms that rightly have focused on reducing the overall costs of healthcare [18][19], coordinating service across the different levels of healthcare [19][20], increasing patient engagement [20], and equal access to health care [18]. In early 2019, three generic patient pathways for mental health and substance abuse were implemented. Later the same year,

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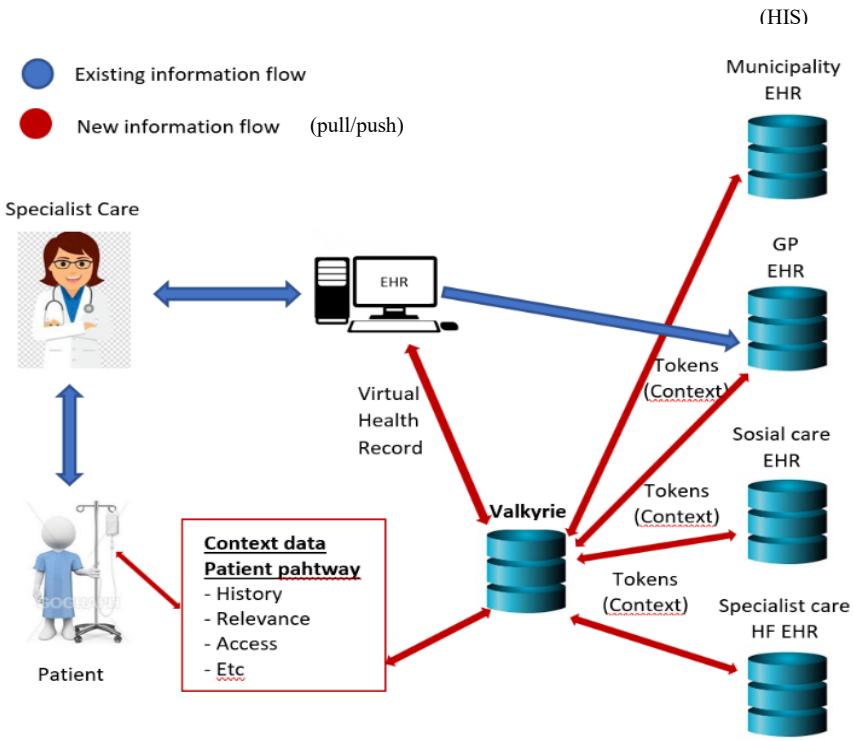

Figure 1: The Valkyrie solution: a simplified architecture

the government issued the first four specific clinical pathways [5]. Research on the implemented clinical pathways for mental health shows that nearly 70% of healthcare professionals believe the pathways, to a small extent or not at all, have contributed to more coherent and coordinated care, and 76% believe pathways, to a small extent or not at all, lead to more user participation and user satisfaction [21].

III. The Valkyrie Solution

To support collaboration between patients, their relatives, and health professionals, patient-centric pathways models are to be based on the Voice of the Patient (VoP) and verified information from experts explaining decisions or variances in the pathway [22].

Research has demonstrated the benefits of using ePHD to model clinical pathways to ensure it is derived factually and objectively from actual occurrences in the patient journey. Still, little research considers a combination of patient-centric design and data-driven to model patient pathways, and even less that approaches it as micro-level modeling. The Valkyrie approach to modeling patient-centric pathways draws on the Norwegian Directory of Health National Plan for Implementation of Patient Pathways [5]. However, it will use a combination of a patient-centric design and a data-driven approach to ensure the micro-level modeling of the patient-centric pathway is derived from actual ePHD occurrences across multiple healthcare levels.

A. Distributed Service-Oriented Architecture

The Valkyrie architecture, Figure 1, supports patient-centric pathways for mental health by delivering a Virtual Health Record (VHR) driven by the requirements of the pathway.

To populate the VHR, each participating HIS pushes a token, encrypted using a public key provided by Valkyrie, whenever an event is recorded in the system for any patient, illustrated in Figure 1. The token carries the patient identifier (unencrypted) and a small set of metadata about the event, including an identifier sufficient to locate the event in the source HIS, and the clinical coding descriptive of the event. The encrypted tokens are transmitted to the Messaging Engine (Valkyrie), which filters the tokens based on the directory of Legitimate Relationships between Valkyrie and individual patients. Tokens for patients without a legitimate relationship are immediately discarded; tokens for patients with a legitimate relationship are stored in the Encrypted Token Store within the Valkyre solution.

To create the Virtual Record Outline for a specific patient, Valkyrie will gather, from the Encrypted Token Store, all encrypted tokens for the patient and decrypt them using Valkyrie's private key, allowing Valkyrie to form the Virtual Record Outline as a timeline of events, some of which may be relevant to the patient-centric pathway. Once the relevance of the events is confirmed in the Resolver (Valkyrie), the Resolver uses the metadata about the event source and locator to request the event view through the Pull Interface of the relevant HIS. When a new patient is added to Valkyrie, messages are sent through the Pull interfaces to each of the

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participating HIS, requesting the push of a set of encrypted tokens for the entire historical record of that patient.

The Blockchain will store the chain of events and status in the patient-centric pathway, together with necessary encrypted metadata, to serve the requests from all the actors. The Microservices will handle logins and message services with push and pull mechanisms through API gateways and interfaces, and enable a scalable and flexible architecture for new, added services when needed. To ensure the correct and relevant presentation of information for each patient and healthcare professional, we will develop an ontology-based semantic layer.

IV. Discussion

The number of persons struggling with mental disorders who need treatment has increased faster than the Norwegian healthcare system was prepared for, putting intense pressure on both primary and specialized care, and the number of clinicians needed to treat them. There is an urgent need to provide this patient group with access to quality care as early as possible to reduce the well-documented adverse long-term effects of such disorders. These patients are less likely to complete their education. They have significant problems getting into the labor market, resulting in higher sick leave costs, various social security costs, the burden of disease, and increased mortality [23]. To complete their care pathway, each person in the target group is in contact with multiple settings across Norwegian healthcare, inevitably resulting in ePHD being distributed in multiple HIS. Valkyrie will enable knowledge transfer across business boundaries and levels of care and facilitate more effective interaction through the patient care pathway.

Valkyrie shall contribute to attaining the objectives of the UN sustainable development goal 3 to ensure healthy lives and promote well-being at all ages, and goal 8 to promote inclusive and sustainable economic growth, employment, and decent work for all.

The Valkyrie project will also contribute new knowledge for the digitalization of the healthcare sector in Norway, specifically relating to HIS scalability, integration, and semantic interoperability. One can identify critical factors for successful implementation by investigating barriers and facilitators and how to cope with them. This knowledge can be used for further implementation of the model and other health interventions; It provides knowledge of the usefulness of a government-initiated action aimed at developing new ways of organizing integrated services. This knowledge will help to enhance healthcare services and improve the quality of care. The Valkyrie project will contribute new knowledge on how the patient´s view of their care pathway is described using standard and open modeling languages and methodologies to ensure scalability and inform the development of patient-centric pathways.

Valkyrie supports two of the three main objectives of the National e-Health Strategy [6], the National e-Health Action Plan 2017-2021 [24], and the strategy of One citizen – One journal [1]. Further, Valkyrie will contribute to five of the six priority areas of the e-Health Plan 2019-2022 [4], namely, tasks 1.1, 2.1, 3.1, 5.1, and 6.1.

V. Conclusion

With the increasing number of individuals struggling with mental disorders and the pressure this puts on the healthcare system, the importance of the coordination of services and the need for information across clinical levels will become more important in the future. Providing access to important patient information and thereby quality care, can reduce the adverse effects of mental disorders and thereby facilitate knowledge transfer, improve interaction across care settings, and provide new knowledge on digitalization and patient-centric care.

The Valkyrie project will contribute new knowledge to the digitalization of the healthcare sector in Norway and support the objectives of the National e-Health Strategy, the National e-Health Action Plan, and the strategy of One citizen – One journal. Investigating barriers and facilitators of the project will provide valuable insights for further implementation and improvement of healthcare services.

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Measuring C-Reactive Protein Using Microring Resonators

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***Abstract*—A rapidly developing application of microring resonators is highly specific biosensing. By covalently binding antibodies to a microring chip, interaction with its corresponding protein will effect a change in mass concentration, which can be read out as an optical wavelength shift. Using low-cost setups for both microfluidic and optical input/output components, we have successfully performed concentration measurements of C-Reactive Protein in order to establish the output sensitivity in the linear regime. We show that the measurement response is highly specific for C-Reactive Protein. Through the use of these commercially available components, we underline the effectiveness and accessibility that microring resonators offer as biosensors.**

***Keywords*: Microring Resonator, Point of Care, Diagnostics, C-Reactive Protein, Biosensor**

I. Introduction

Microring resonators (MRRs) are optical sensors that are able to measure changes in the refractive index of fluid samples accurately. This is done by coupling laser light into a waveguide, from where its evanescent field reaches an adjacent microring [1] [2]. Due to the evanescent field of the microring itself, the total optical path length of the ring also depends on the fluid that runs on top of the ring. By sweeping the wavelength of the laser light, the relative effective refractive index n_{eff} of a ring of length L, can be determined from resonant wavelength(s) λ_m

$$\lambda_m = \frac{L \cdot n_{eff}}{m}, \tag{1}$$

corresponding to resonance mode m = 1,2,3.., . Covalently binding antibodies to the microring allows this process to be used for biosensing, allowing only a specific protein to bind and enact such a change in relative refractive index [3]. By performing these measurements at different protein concentrations, the sensitivity *s* of the sensor can be determined, which is defined as the change in relative refractive index per unit of protein concentration. The setup required to perform protein measurements with MRRs is dependent on two additional systems: an optical setup to couple laser light into a sensor chip and read out the resonant wavelengths, and a microfluidic setup to flow the protein samples over the sensor chip [4]. This paper discusses the MRR setup using low-cost, readily available components, and presents representative measurements on C-reactive protein [5]. The measurement setup shows a high specificity for C-reactive protein and an improved speed of operation when compared to literature [6]. In Section 2, we give an overview of the developed measurement setup. In Section 3, the concentration measurements of C-reactive protein are discussed, starting with an explanation of the used measurement protocol, followed by the gathered results. Section 4 offers the conclusion that follows from these results and a discussion thereof.

II. Low-Cost Setup

In this section, we discuss the different setup components that have been developed, namely the optical and microfluidic subsystems.

A. Optical Input and Readout

For the optical system, an Agilent 8164A sweeping laser was connected as the input and a PicoScope 2206B computer oscilloscope as the readout device. To control the laser light in the microring resonator, an Agilent 8164A Lightwave Measurement System was used with an Agilent 81640A Tunable Laser as the active module. This system can perform a laser sweep in a wavelength range of 1400-1670 nm, allowing the setup to continuously search for resonant wavelengths in a set range. The different Agilent instruments are synchronized via TTL triggers. The chip holder stage allows for translation and rotation in the horizontal plane, and is used to get a consistent alignment of the sensor chip and makes it possible to couple light into the chip at different points. Note that this subsystem functions as a proof of concept; the concentration measurements in Section 3 are performed using the Delta Diagnostics MRR.

B. Microfluidic Components

For the microfluidic system, a Harvard Apparatus 33 DDS syringe pump and AMF RVMLP rotary valve have been integrated. All of these instruments are controlled through a single Graphical User Interface (GUI) that has been developed in Python, allowing for platform-independent usage. The Harvard Apparatus 33 DDS syringe pump produces a vacuum to move the liquids through the setup by having a stepper motor move the plunger of an inserted syringe. Rather than connecting

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various syringes with different samples in sequence that are pushed through the setup, the choice is made to have the syringe pump create a vacuum and use the syringe as a waste container that the samples are drawn into. This does necessitate the use of a rotary valve in order to selectively draw from the samples. Fluids that are to be used during an experiment are first stored in Eppendorf tubes, which are connected to an AMF RVMLP rotary valve. After passing the rotary valve, a fluid is drawn over the MRR-chip that is sealed of with a flow cell. Before ending up in the syringe, the flow speed of the liquid is measured in an Elveflow MFS4 flow sensor, the results of which can be read out via the accompanying software. The tubing between the Eppendorf tubes and the rotary valve has an inner diameter of 0.2 mm, in order to minimize the amount of reagents that is wasted while purging. The rest of the tubing has an inner diameter of 0.8 mm. A schematic overview of the complete microfluidic setup is shown in Figure 1.

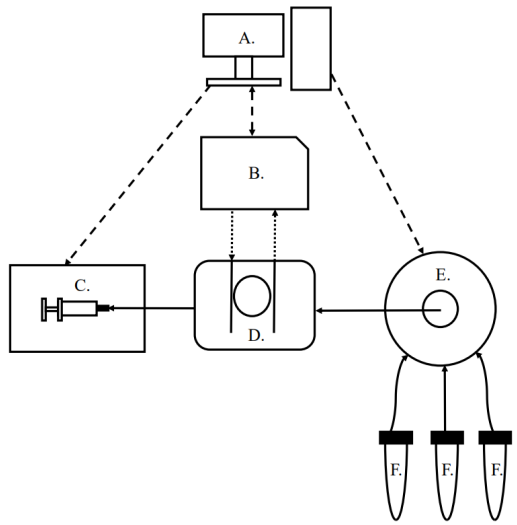

Fig. 1. *Schematic overview of the microfluidic setup, consisting of the following components: A. Measurement PC; B. Delta Diagnostics MRR; C. Harvard 33 DDS syringe pump; D. MRR chip; E. AMF RVMLP rotary valve; F. Eppendorf tubes containing reagents.*

III. C-Reactive Protein

This section shows the application of the developed setup in performing concentration measurements of C-reactive protein.

A. Concentration Measurement Method

The sensor chip that is used contains six microrings, and has been coated with a hydrogel by XanTec. Of these six rings, ring 4 is covered with a silicon-oxide layer, which shields the microring from the reagents and allows it to function as a reference regarding pressure and temperature influences. The hydrogel serves as the base layer upon which the antibodies are placed. The chip is functionalized with mouse-derived CRP-antibodies, acquired from ThermoFisher. Before the actual start of a measurement, the tubing is purged to prevent contamination during the experiment. The CRP has been dissolved in Phosphate-Buffered Saline solution with Tween (PBST). This buffer solution does not interact with the protein, and allows for a stable reference measurement if no CRP is dissolved in it. A concentration measurement starts by regenerating the sensor chip, or removing contaminants, by flowing the buffer solution, followed by a 50 mM glycine solution, and another round of the buffer solution. This is done for 1 minute per reagent, with a flow speed of 100 µl/min. Once the regeneration process is completed, the buffer solution is flowed over the sensor chip with a flow speed of 20 µl/min for 5 minutes to create a stable readout baseline. Then, the CRP sample is introduced, likewise by flowing at 20 µl/min for 5 minutes, followed by the buffer solution. It is during this final step that the response is determined, at a set time after switching to the buffer solution, to ensure that the measured response is a result of protein-antibody interaction rather than electrostatic attraction of the protein. Afterwards, the regeneration process is repeated in order to quickly remove all of the bound protein from the chip.

B. Dose-Response Results

Measurements have been performed with doses of 0.3, 1.0, 3.0 and 10 µg/ml CRP. The measurement of 10 µg/ml is shown in Figure 2 as an example. It can be seen how rings 1, 5, and 6 show a response when the CRP sample is introduced, which slowly moves toward an equilibrium state where the rate of association and dissociation between the CRP and the antibodies are equal. The difference in response between these rings can be explained by the fact that they are placed in a straight line on the sensor chip: the CRP first reaches ring 1, thereby lowering the amount of available molecules in the sample that reaches the later rings. It is unclear why rings 2 and 3 show a lower response.

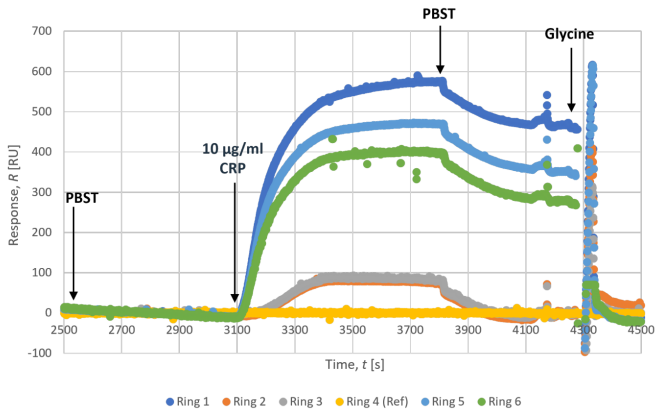

Fig. 2. *Results of concentration measurements of samples with a CRP concentration of 10 µg/ml. Only ring 1, 5 and 6 are functionalized with mouse-derived anti-CRP.*

By repeating this measurement at different concentrations, a dose-response curve can be created, as is shown in Figures 3-5 for the individual rings. The corresponding fit values are included in Table I. The measurement results of ring 1, 5 and

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6 are presented in Figures 3-5. The response of the measured complex (CRP binding with anti-CRP) is plotted against the dose, in which the x-axis is plotted logarithmically. The fit for the dose response curve is obtained by using non-linear regression in Python with the curve fit function from Scipy with the Levenberg-Marquardt algorithm. The resulting fit parameters for ring 1, 5 and 6 are listed in Table I. From these fits, the sensitivity s has been determined, resulting into s_1 = (80±12) RU(µg/ml)$^{-1}$, s_5 = (76±5) RU(µg/ml)$^{-1}$ and s_6= (77±10) RU(µg/ml)$^{-1}$ for rings 1, 5 and 6 respectively.

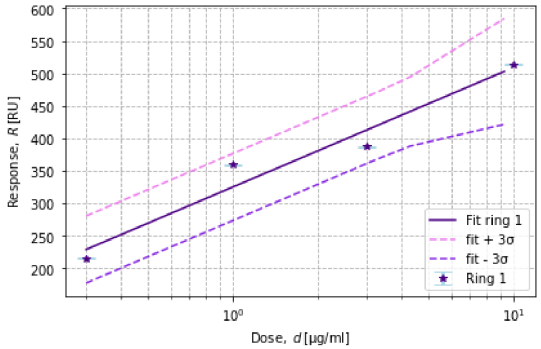

Fig. 3. Dose-response curves for ring 1 of the formed CRP complexes with mouse-derived anti-CRP.

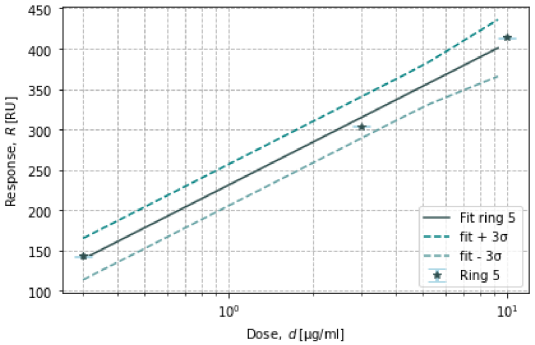

Fig. 4. Dose-response curves for ring 5 of the formed CRP complexes with mouse-derived anti-CRP.

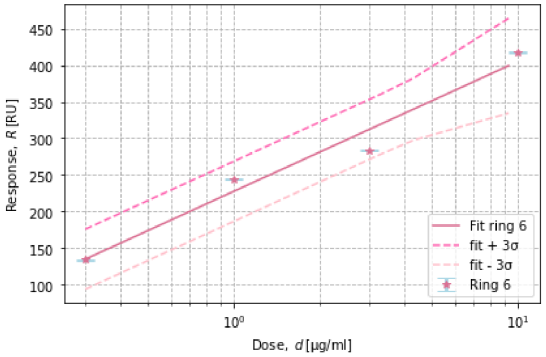

Fig. 5. Dose-response curves for ring 6 of the formed CRP complexes with anti-CRP produced in a mouse from the company ThermoFisher.

TABLE I
MEASUREMENT RESULTS

Ring	Fit Values
1	$R(d) = (80 \pm 12) \cdot \log(d) + (324 \pm 17)$
5	$R(d) = (76 \pm 5) \cdot \log(d) + (231 \pm 9)$
6	$R(d) = (77 \pm 10) \cdot \log(d) + (228 \pm 14)$

IV. CONCLUSION AND DISCUSSION

In this paper, we have outlined a method to create a low-cost optical and microfluidic setup that can be used to perform biosensing experiments with microring resonators. To prove this concept and display the accessibility of this technique, we have successfully performed concentration measurements of C-Reactive Protein. The determined sensitivity s of the setup is (80±12) RU(µg/ml)$^{-1}$, (76±5) RU(µg/ml)$^{-1}$ and (77±10) RU(µg/ml)$^{-1}$ for the three different microrings on the sensor chip. The relatively large uncertainty is caused by the limited amount of different concentrations that have been measured due to time constraints. This implies that the uncertainty can be reduced without further investments. Furthermore, these measurements have only been performed in the linear regime of the dose-response curve. It is not yet clear what the lower limit of detection of the setup is and, while unlikely, whether the setup will influence the sensitivity near the upper limit of its dynamic range.

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Assessing Well-Being in Spain in the Post-COVID Era: A Population Study Using Mobile Sensors and Experience Sampling

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***Abstract*—The coronavirus outbreak has impacted severely the well-being of populations all around the world. All of a sudden, people had to shift to remote work and social distancing measures, which resulted in profound changes to daily routines, causing stress, anxiety, and depression. Hence, it is important to understand the effects of COVID-19 on the well-being of populations, in order to make informed decisions on public health interventions and policy recommendations. This paper presents the first population study conducted within the context of the POSTCOVID-AI project, which combines mobile sensing and artificial intelligence techniques to shed new light on the impact of COVID-19 on the well-being of the Spanish population. The aim of this article is to present the methodological framework, data collection, and preliminary results generated for this study, as well as the future directions towards the achievement of the goal of the project.**

Index Terms*—COVID-19; smartphones; sensors; experience sampling; well-being.

I. Introduction

The outbreak of the coronavirus disease (COVID-19) has had a profound impact on the well-being of populations around the globe. The unexpected shift to remote work and social distancing measures resulted in significant changes to daily routines, causing stress, anxiety, and depression in many individuals. The pandemic has also illustrated clear disparities in our societies, with certain populations, such as those living in poverty, marginalized communities, and essential workers, being disproportionately affected. Additionally, the economic consequences of the pandemic have also led to financial stress and insecurity for many households.

After a few years, the pandemic has been brought generally under control, mostly thanks to the widespread use of diagnostic tests [1], administration of vaccines [2] and the remarkable efforts of healthcare workers and scientists. Nonetheless, it is of much importance to understand the direct and indirect effects of COVID-19 on the well-being of populations. In particular, studies on the impact of the pandemic on well-being can provide, for example, insights into its long-term consequences, such as post-traumatic stress disorder and other mental health conditions [3]. Likewise, this type of studies can also enlighten us to have a better understanding on other important social consequences, like increased feelings of loneliness and isolation for many individuals, particularly for older adults and those living alone [4].

Spain was one of the countries hardest hit by the COVID-19 pandemic, with a high number of cases and deaths reported in the first wave of the pandemic [5]. The Spanish government implemented strict lockdowns and social distancing measures, which had a significant impact on the daily lives of individuals

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and families. The Spanish economy was also greatly impacted by the pandemic, with high levels of unemployment and financial insecurity reported.

According to recent studies, the Spanish population experienced a range of negative impacts on their well-being as a result of the COVID-19 pandemic. One study found that the pandemic led to increased levels of stress, anxiety, and depression among the Spanish population, particularly among those who were directly affected by the illness, such as healthcare workers, and those who lost loved ones [6]. Another study reported that the lockdowns and social distancing measures resulted in increased levels of loneliness and social isolation, which can have long-term consequences for mental health [7]. In addition to the psychological effects, the economic consequences of the pandemic have also had a significant impact on the well-being of the Spanish population. Some studies reported that the pandemic has resulted in increased levels of poverty, particularly among marginalized populations, such as immigrants and single-parent families [8].

Great efforts have been made both in Spain and globally to comprehend better the consequences of the pandemic. Several studies have been conducted to that end, normally by means of one-shot surveys. Some works particularly relied on the use of digital questionnaires, which could be filled in via a web browser [9] or a mobile app [10], [11]. More sophisticated approaches adding mobile sensing features have been also developed to measure diverse social and behavioural indicators for small population samples [12]. Many such studies took place during the early phases of the COVID outbreak, particularly during or right after the lockdowns. Nonetheless, many more efforts are needed, especially now and in the years to come, to track the evolution of the well-being of the population. In light of this necessity of follow-up data on the effects of the pandemic, we contribute with POSTCOVID-AI, a project aimed at providing a longitudinal and holistic description of relevant factors associated to population well-being during the post-pandemic era. The project overarching goal is to build an AI-driven system to automatically and continuously monitor and analyse population-level indicators relating to physical activity, social interactions, and emotional states, among others, as well as their links to general well-being. In this paper, we present the overall idea behind POSTCOVID-AI and the first population study conducted within the project using the developed digital tools. Moreover, initial results and findings derived from this study are briefly outlined.

The remainder of the paper is as follows. Section II describes the POSTCOVID-AI intelligent system. Section III describes the study conducted and the preliminary results are shown in Section IV. The main conclusions and next steps are outlined in Section V.

II. POSTCOVID-AI

POSTCOVID-AI is a novel framework that employs real-time acquisition and analysis of social, behavioral, and emotional data to assess the impact of the post-COVID-19 context on the well-being of the Spanish population. Leveraging the widespread use of smartphones among most segments of the population, POSTCOVID-AI continuously and anonymously monitors social, behavioral, and emotional data at both the individual and group levels. The framework combines digital sensing and artificial intelligence techniques to process raw, anonymous, and mobile big data into meaningful longitudinal representations of the social, behavioral, and emotional states of the population. These representations are then used to identify relevant patterns and tipping points that may impact well-being, as well as to predict its future evolution.

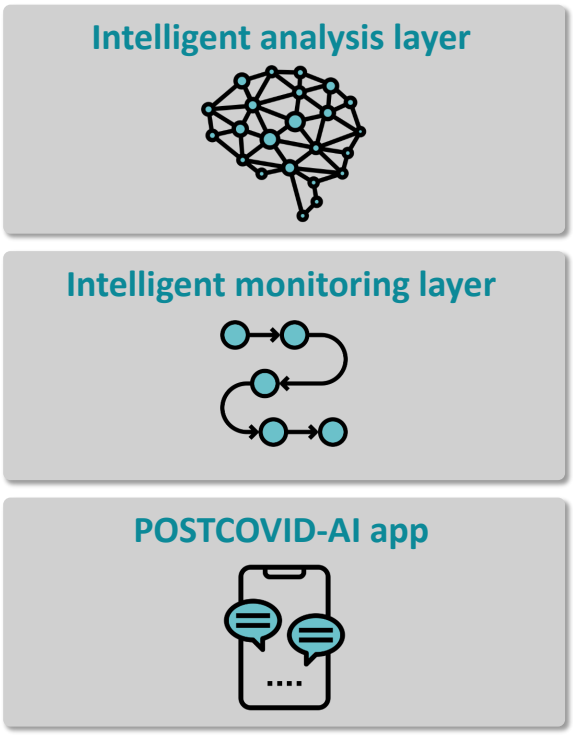

Fig. 1. POSTCOVID-AI high-level architecture.

POSTCOVID-AI relies on a two-layered methodological framework and a mobile app, schematically presented in Fig. 1.

The POSTCOVID-AI app is designed to gather both objective and subjective data from individuals in real-time to monitor the impact of post-COVID-19 context on the well-being of the population. This is achieved via the integration of built-in smartphone sensors and digital questionnaires. Objective data is collected passively using the smartphone's built-in sensors, such as the light sensor to monitor sleep patterns, accelerometry to monitor activity levels, audio level to measure environmental noise, and Bluetooth/WiFi/GSM to measure interactions with others. The app also uses Experience Sampling Methods (ESMs) to collect self-reported data related to health status, emotions, and subjective well-being. The collected data includes demographic information, COVID-19 related information, emotional, social, behavioral, and well-being data, providing a comprehensive view of the social,

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behavioral, emotional, and well-being states of each individual. The data is anonymised and securely transferred to a central data center for aggregation, harmonization, and analysis. The vast amount of data collected by POSTCOVID-AI app enables the use of innovative machine learning and artificial intelligence methods to generate new knowledge and insights into the impact of this and similar pandemic on people's well-being.

The intelligent monitoring layer comprises all the mechanisms for gathering, aggregating and harmonising (i.e., cleaning, transforming and normalizing) the data collected anonymously via the POSTCOVID-AI app. The dataset harmonisation task prepares the recorded data for processing. It includes the labelling, coding, adaptation, cleansing and wrangling of the data so that they can be processed by the analytical routines implemented in the intelligent analysis layer. This task also ensures the full anonymisation of the data for its public sharing. As a result, a comprehensive big dataset of harmonised mobile data is produced.

The intelligent analysis layer sophisticatedly processes the harmonised mobile big dataset in order to generate more interpretable contextual and factual information describing the social, behavioural and emotional situation of the individuals, thus creating a multivariate longitudinal dataset. To that end, machine learning techniques are used, such as clustering algorithms (e.g., principal component analysis, deep clustering networks) to group and select statistically relevant and non-redundant mobile data features. Advanced classification algorithms (e.g., support vector machines, convolutional neural networks) are applied to translate these data features into categorical and numerical indicators describing social, behavioural and emotional states. As an example, body motion registered via the phone accelerometer sensor is transformed into physical activity labels of the type "sitting", "walking" and the like. As a result, a collection of rich time series variables or indicators is generated, which quantify aspects such as the overall mood or activity performed at home vs. outdoors, during daytime vs. night-time, in weekdays vs. weekends, etc. The resulting unique multivariate longitudinal dataset is continuously and automatically analysed via artificial intelligence algorithms to generate new knowledge and evidence on how past and present events are affecting and will affect the population's well-being. More specifically, multivariate pattern mining techniques (e.g., vector autoregressive integrated moving average, dynamic programming change point detection) are used to determine individual and population level tendencies and change points, such as a positive a trend in the number of hours spent at home or a decrease in the sleeping hours linked to a negative trend in the general state of mind. All these analytical findings are then mapped to the reported individual and population well-being.

III. Population study

The participant sample for this study was sourced through a market research company that established a panel of individuals meeting the specific requirements of the study. The selection process employed a quota stratified sampling methodology to ensure representation of the Spanish population in terms of gender, age, location, and annual income.

Before the study began, candidates were provided with a detailed information sheet that outlined the study's parameters, including its duration and start date, the number of surveys to be completed, and the frequency of their completion, as well as data privacy considerations. The rewards for participating were also outlined, with a minimum of 80% completion rate of the daily surveys required to receive the reward.

All study procedures were conducted in accordance with relevant ethical guidelines and regulations. The study was approved by the Ethical Committee of the University of Granada under reference number 2214/CEIH/2021. Prior to participating, all individuals provided informed consent and confirmed that they were at least 18 years old. Participation in the study was strictly voluntary and all data collected was anonymous and confidential. The study adhered to the ethical standards outlined in the Declaration of Helsinki.

A total of 110 individuals completed the minimum required registration period (i.e., November 15, 2021 to December 15, 2021). During the study, 7 participants withdrew, but they were promptly replaced with other individuals with similar characteristics. The participants were composed of 53 (48.2%) females and 57 (51.8%) males, with ages ranging from 18 to 70 years (mean±std age=44.3±16.1). Annual net income was classified according to the criteria established by the Spanish Statistical Institute (INE). To ensure representation of the diverse Spanish population, the Nielsen Geographic Zones criteria were used. Of the 110 participants, 77 (70%) completed 80% or more of the surveys.

For the data collection, the study participants were required to install the POSTCOVID-AI app on their smartphones, enter the identification number provided by the recruitment company, grant the necessary permissions for the app's proper functioning, and provide their digital informed consent to participate in the study. As a part of the enrollment process, participants were asked to complete an initial survey, which included demographic and COVID-19 related information, as well as questionnaires aimed at measuring their well-being.

Once enrolled, the app initiated the passive data collection through the smartphone's sensors, including physical activity recognition, and indicators of social activity such as connection type, screen usage, WiFi networks, ambient light, and noise. Moreover, the self-reported emotional data was collected using the ESMs implemented through the app. The app pushed notifications to participants at six designated times per day, randomly distributed between 7:00-8:00, 10:00-11:00, 13:00-14:00, 16:00-17:00, 19:00-20:00, and 22:00-23:00. The notification persisted for one hour before disappearing. Upon opening the notification, the app prompted participants to complete the corresponding survey, which was then transmitted to the data storage server. In addition to the daily surveys, the app prompted participants to complete weekly questionnaires on their socio-economic, health, and well-being status, to monitor any changes over time. Table I outlines the different data types, variables, and indicators collected via the phone.

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TABLE I
OVERVIEW OF THE DATA COLLECTED IN THE POPULATION STUDY.

Data type	Variable	Instruments or Indicators
Sensor	Activity recognition	Detected physical activities
	Wifi	Connections to WiFi networks
	Connectivity	Type of connections with the network
	Light	Ambient light measurements
	Noise	Ambient noise measurements
	Screen	Smartphone screen status
Initial Survey	Participant's characteristics	Questions on socio-demographic and COVID-19 related data
	Psychological measures	International PANAS Short Form (I-PANAS-SF)
		General life satisfaction and seven domain of life
		Flourishing Scale (FS)
		Patient Health Questionnaire – 9 (PHQ-9)
		Generalized Anxiety Disorder Scale (GAD-7)
		Brief Resilience Scale (BRS)
		Acceptance And Action Questionnaire – II (AAQ-II)
Daily Survey	Affect	Valence
		Energetic Arousal
		Tense Arousal
	Emotional event	Report on any remarkable situations at the emotional level
Weekly Survey	Follow up variables	Questions on socio-demographic and COVID-19 related data
		General life satisfaction and seven domain of life

IV. PRELIMINARY RESULTS

The dataset obtained in the initial POSTCOVID-AI study, which will be publicly released soon, encompasses a diverse array of variables, as described above. Among the most salient data is the mood of the study participants. Following the preprocessing of mood data collected from daily surveys, we identified 57 participants with an adequate number of responses, constituting at least 80% of the 180 total responses recorded over the course of the month-long study. This will allow us to calculate indices of psychological well-being. The sample comprised 30 male participants (53%) and 27 female participants (47%). The mean age of participants was 44 years with a standard deviation (SD) of 17 years. The youngest participant was 18 years old and the oldest was 70 years old.

In terms of the psychological characteristics of the participants, based on the questionnaires administered at the start of the study, we compared the results to mean scores of the general pre-pandemic population as reported in prior studies. Specifically, our participants had a mean score of 5.95 (SD = 4.85) on the Generalized Anxiety Disorder Scale - 7 (GAD-7), which indicates a mild level of anxiety. The mean score of the general population in Spain prior to the pandemic was 3.54 (SD = 3.32). On the Patient Health Questionnaire - 9 (PHQ-9), our participants had a mean score of 6.86 (SD = 4.72), reflecting a mild level of depression. The mean score of the general population prior to the pandemic was 2.91 (SD = 3.52). All the responses of each participant for the GAD-7 and the PHQ-9 are shown in Fig. 2 and Fig. 3 respectively.

These findings suggest that our participants exhibit slightly elevated levels of both anxiety and depression compared to those reported in previous studies of the general population prior to the pandemic. These results are consistent with those obtained in another study involving almost 2000 participants conducted during the pandemic in Spain, with a mean GAD-7 score of 5.86 (SD = 5.24) and a PHQ-9 score of 6.50 (SD = 5.65). This supports the validity of the data and reiterates the mental health impacts of the pandemic that have been documented in multiple studies. Our group's aim is to carry out further studies to validate these results.

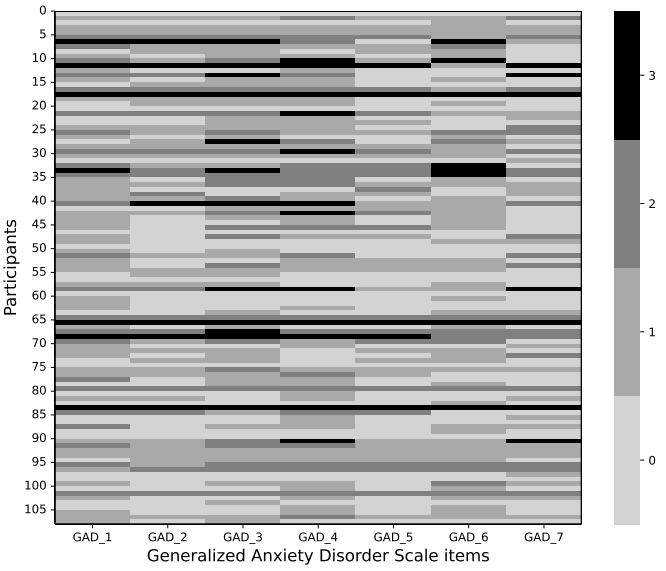

Fig. 2. Generalized Anxiety Disorder Scale (GAD-7) responses of each participant. The seven items address how often participants have been bothered by any of the following problems: GAD 1 - "Feeling nervous, anxious or on edge"; GAD 2 - "Not being able to stop or control worrying"; GAD 3 - "Worrying too much about different things"; GAD 4 - "Trouble relaxing"; GAD 5 - "Being so restless that it is hard to sit still"; GAD 6 - "Becoming easily annoyed or irritable"; GAD 7 - "Feeling afraid as if something awful might happen". Each item of the scale (GAD x) is scored with a 0, 1, 2, or 3 value.

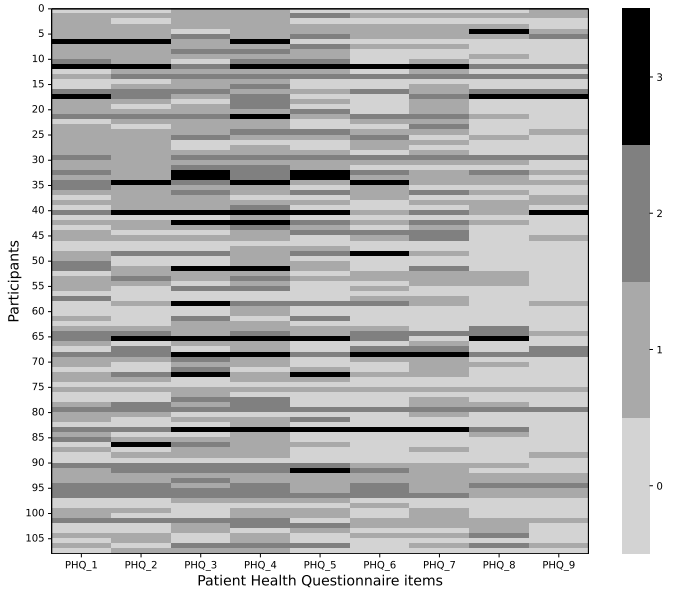

Fig. 3. Patient Health Questionnaire (PHQ-9) responses of each participant. The nine items address how often participants have been bothered by any of the following problems: PHQ 1 - "Little interest or pleasure in doing things"; PHQ 2 - "Feeling down, depressed, or hopeless"; PHQ 3 - "Trouble falling or staying asleep, or sleeping too much"; PHQ 4 - "Feeling tired or having little energy"; PHQ 5 - "Poor appetite or overeating"; PHQ 6 - "Feeling bad about yourself - or that you are a failure or have let yourself or your family down"; PHQ 7 - "Trouble concentrating on things, such as reading the newspaper or watching television"; PHQ 8 - "Moving or speaking so slowly that other people could have noticed? Or the opposite - being so fidgety or restless that you have been moving around a lot more than usual"; PHQ 9 - "Thoughts that you would be better off dead or of hurting yourself in some way". Each item of the scale (PHQ x) is scored with a 0, 1, 2, or 3 value.

V. Conclusion

The COVID-19 pandemic has had a profound impact on the well-being of populations around the world, with the Spanish population being no exception. The pandemic has resulted in increased levels of stress, anxiety, depression, loneliness, and financial insecurity, among other negative impacts. Nonetheless, further research is needed to fully understand the long-term consequences of the pandemic on the well-being of populations.

In this work, we introduced POSTCOVID-AI, an on-going project that aims to continue monitoring the effects of the pandemic on the population well-being. In doing so, the project ambitions to objectively inform governments, health organizations, and communities to help them implement interventions and policies that address the psychological and economic consequences of the pandemic, and support the most vulnerable populations.

A first population study has been conducted in Spain showing the potential of the proposed approach. At this time, the project team is undergoing the curation of the collected data, which will be made open access soon. A preliminary analysis of the data confirm that both anxiety and depression hold after the most severe phase of the pandemic, thus confirming the need to keep on tracking the well-being of the population, with the overarching goal of supporting individuals and families as they navigate this challenging time.

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