BioMed Wizard
An Approach for Gathering Personal Risk Factor Data

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Abstract: People can be at risk of developing some serious diseases without being aware of it. Such diseases either do not present symptoms in early stages or have simple symptoms that are ignored or not properly identified by patients, due to their lack of medical know-how. On the other hand, in order to provide patients with early indications of their risk level on developing such diseases, specially for chronic diseases such as diabetes type 2, it is necessary to collect substantial amount of personal data about risk factors related to the disease. A smart wizard software applying the approach developed in our study, which brings awareness about some socio-economical concerns of patients, can increase patients’ engagement in providing their personal data. The case study focuses on the diabetes type 2 and some socio-economical concerns of patients, including privacy invasion, time, and cost. In this research, the willingness of a sample group of more than 100 people is surveyed, in providing their personal data, for three different scenarios and related to nine main risk factors. The results collected in this survey is then applied to develop four user-specific data collection flow models, to be implemented in a smart wizard software.

1 INTRODUCTION AND RESEARCH APPROACH

For a number of diseases, people can be at risk of developing them, without being aware. Such diseases do not present symptoms in early stages or have symptoms that are typically ignored or not properly identified by patients due to their lack of medical know-how in identifying symptoms. However, it is very important to recognize diseases in their early stages of development, in order to reduce the chance of life threatening situations. An example of a disease that can develop without alarming with early symptoms, is diabetes mellitus type 2. This is a chronic disease that causes high levels of glucose in the blood. Diabetes can result in serious complications such as heart disease and stroke, obesity, high blood pressure, blindness, kidney disease, nervous system related diseases and more (Zhang and Zhao, 2013).

According to the World Health Organization, in 2012, 1.5 million deaths were directly caused by diabetes (World Health Organization, 2014) demonstrating the importance of detecting the risk of diabetes for the general public in an early stage. Diabetes type 2 can be developed during any stage of ones life. Several risk factors are known to be associated to this disease, which vary from someones lifestyle that can influence the risk of developing diabetes type 2, but also inheritance (i.e DNA) can be of influence. Therefore, people are not always aware of being in risk of developing diabetes. Although lack of exercising and consuming unhealthy food might not have a direct (negative) influence on someone, but it increases his/her chance of developing the disease. Early detection can reduce the burden of complications of diabetes, if treated on time (Knowler et al., 2002). As such bringing awareness and insight of the possible risk level of developing diabetes, based on information provided about current personal habits and status (i.e risk factors), will definitely help with this illness. Although many researchers have designed prediction models for risk of developing type 2 diabetes( Abbasi et al., 2012), the current process of assessing the risk of developing a disease entails setting appointments with general practitioners or specialists as a starting point, followed by conducting a blood test. This can be a time consuming and costly process for diagnosing the risks at the early stages. To reduce the time and cost of such process, and in order to have a more extensive coverage of the assessment process, one would like to only perform such a process when necessary and after an initial screening and diagnosis process.
There are online software wizards that provide users with information about diabetes, but these are often only based on a limited number of risk factors (e.g. only asking about the gender). For example after a gender selection option, the online wizard provides all risk factors and symptoms specific for that specific gender. Although this could be helpful, it still very much leaves the assessment of the risk level to the patients, and depends on the proper identification of the symptoms by them. However, the indication of the patients risk level can be further clarified and can be made more precise if more risk factors are measured or identified from the user. For example tools such as the Diabetes Risk Score (Lindström and Tuomilehto, 2003) use information about certain risk factors such as age, BMI and diet to calculate a score that indicates the risk level of developing diabetes type 2.

In this research we aim to develop an approach for user specific data collection that can be developed within a smart wizard software to provide users with an indication of their current risk level, with the consideration of socio-economic aspects in the collection process. A smart wizard software automatically adapts future data collection based on the data that the user has provided up to that stage. By doing so, the software creates a user specific flow for entering data, helping the user to traverse through the process, making it easier, faster, and more efficient in a user centric manner. In the case of this research the focus is more on what, how, in which order, and how frequently to collect risk factor data. Next to focusing on these, we focus on factors such as cost, time, and the needed effort, since these are also factors that play important roles on the willingness of someone to share data. Therefore, socio-economic aspects are also taken into consideration. The goal here is to get insight on what data can be realistically gathered and from where, and how it can be gathered for different types of scenarios when considering different phases of screening for diabetes as an example disease. As such in this research we try to answer the following research question:

How can personal data be collected from users when considering socio-economic barriers?

In order to address this research question a five-phase research approach has been designed, consisting of the following phases: 1) Identification of Main Risk Factors and Relevant Bio-markers, 2) Design of the Survey, 3) Evaluation of the Survey, 4) Conducting the Survey, and 5) Analysis of Results and Design of User Specific Data Collection Flow Models.

2 RELATED WORK

With the introduction of electronic medical files, created and stored in digital systems, it became more easy to share medical information. Later with the introduction of electronic health records (EHRs), electronically sharing medical information about patients with third parties became feasible and trivial for hospitals upon the request of patients. This provided patients with more control over the availability of their medical information.

Although research in 2009 (Jha et al., 2009) shows that US hospitals still struggle to implement the electronic forms of health records (9.1% make use of a basic EHR system), a study in 2014 (Adler-Milstein et al., 2014) showed that at least 50% of the US hospitals make use of a basic EHR system. This adoption is not limited to hospitals, but also other medical professions, such as physicians, show an increasing trend of using EHR systems (Xierali et al., 2013). These studies show that EHR systems are becoming more popular and the use of them will continue to rise in the coming years. Since these electronic health records contain medical data about the patient, information about risk factors are likely to be found in these files. A study in 2009 (Hivert et al., 2009) used information stored in electronic health records to find patterns that identify patients with metabolic syndrome that would put them at larger risk of becoming obese and develop diabetes. This study demonstrated that electronic health records can play an important role as data sources in identifying patients with a risk of developing diseases.

Although such sources of data look promising one must investigate the level of willingness and the situation in which people are willing to provide access to their electronic health records. Studies have investigated the willingness of users to share information in general for a certain cause. A study (Teixeira et al., 2011) has investigated the willingness of HIV patients to share personal health information with others. The founding of the study suggests that the vast majority (84%) are willing to share this data electronically, but the individuals who would receive the shared data have to be involved in the direct care of the patient. Fewer patients (39%) are willing to share it with non-carers electronically. Another study (Beckjord et al., 2011) has looked into the willingness of cancer patients to exchange personal related information electronically. They have compared participants who are diagnosed with cancer against participants who are not diagnosed, and have found that people who are diagnosed are much more willing to share this information to help others. A research done in 2014 (Pickard and Swan, 2014) has concluded that there is a strong
willingness of people to share personal data in order to enable next generation health care services, ultimately leading to improved health outcomes for all.

These findings suggest that people are willing to share personal information electronically, which is also an important requirement for a smart wizard software, but these studies also suggest that the amount of information shared differ depending on the amount of engagement the patient has in a specific disease and how the share of this information directly influences their health conditions. In this research we further investigate the willingness of people in sharing personal information in a more fine grained manner (i.e bio-markers’ level) while taking into account the influence of their profile (i.e demographics and engagement with disease) and will investigate the possibility of adjusting data collection based on the users profile and level of engagement.

3 IDENTIFICATION OF RISK FACTORS AND RELEVANT BIO-MARKERS

There are many studies on individual risk factors related to diabetes mellitus type 2, such as obesity (Tirosh et al., 2011), diet (Montonen et al., 2004) and ethnicity (Harris, 2001) but Mayo Clinic (Mayo Clinic, 2015) and the Dutch National Institute for Public Health and Environment (Rijksinstituut voor Volksgezondheid en Milieu, 2013), have provided an extensive collection of the main risk factors including: age, obesity, ethnicity, family history, genetic factors, diet, smoking behavior, pre-diabetes, gestational diabetes (pregnancy diabetes) and (in)activity. But in order to assess the risk level of developing diabetes type 2, we are interested in collecting bio-markers related to risk factors. Bio-markers are aspects of the body that can be measured in order to understand the current condition of the risk factors. As an example, for the risk factor obesity, BMI (Body Mass Index) can be considered as a bio-marker and can be calculated based on two other measurable bio-markers being the height and weight of the patient. The same applies in the case of genome factors, where the genome sequence is considered, so that research can focus on the specific parts needed to determine the genome factors regarding diabetes.

Although most risk factors can easily be mapped to a bio-marker and are easily perceived, there are others that are perceived differently by different people such as being active or not (Shephard, 2003). This makes the measurement of these risk factors unreliable (Prince et al., 2008). Such risk factors have not been incorporated in this research as covering all possible perspectives of such risk factors (e.g. cycling as a perspective to measure activity) is not feasible and would cause misinterpretation of the results of this research.

Based on the above for the proof of concept, only 9 main risk factors/bio-markers have been selected in order to be incorporated into the survey, including: age, weight, height, ethnicity, family history, genome sequence, diet, smoking behavior and pre-/pregnancy diabetes. This is also due to the fact that in this research we are not focused on identifying all possible risk factors or providing the best possible risk prediction model, rather investigating the feasibility of a personalized data collection experience to reduce socio-economical barriers.

4 DESIGN OF THE SURVEY

In order to measure the willingness of people to share information about risk factors, a survey has been conducted. The guidelines suggested by the literature (Fink, 2012; Dörnyei and Taguchi, 2010) have been followed to ensure the validity and quality of the results and the conclusions. The survey is designed in a manner which:

i) provides confidence that the questions are answered with appropriate awareness,

ii) the engagement of the participants in the survey is maximized, and

iii) false responses, due to privacy concerns or boredom, is minimized. To achieve the above a set of rules have been designed, that the survey should comply to:

1) The time needed to answer all questions should be approximately 5 minutes;

2) The questionnaire should not contain more than 30 questions;

3) The questionnaire should be available in the language of the majority of the sample population (Dutch) and in English;

4) Only complete submissions are acceptable, as such, partially filled questionnaires are not acceptable;

5) The survey should be conducted in a completely anonymous manner;

6) The minimum age of the participants should be 18;

The questionnaire of the survey has been designed in a manner that for each bio-marker, the participants will be asked to respond to four types of questions:

Situation Questions. As we are interested in considering different phases of screening, four different scenarios with an increasing level of confidentiality have been designed: 1) Social chatting 2) (General) research 3) Family related 4) Diagnosed

Each scenario has been fitted with an appropriate image to visually attach the participant to the scenario and a line of text representing the situation. For each
bio-marker, participants are asked to select in what situation(s)/scenario(s) they would provide information regarding that specific bio-marker. Participants can select none, one or more options. If one or more options are selected, follow-up questions will be presented to them regarding that specific bio-marker otherwise they can proceed to the question(s) about another bio-marker.

Means of Providing Information. If the participant selects one or more scenarios, he/she is asked about the means of which he/she prefers providing information about the specific bio-marker in the specific scenario(s). All bio-markers are provided with the option to manually provide information as well as through an electronic health record (EHR). We have assumed that if EHR is chosen as a means of providing bio-marker information, then this information in definitely available in the EHR of the participant. Besides these two options, several bio-markers have other option. Age can also be shared through social networks. The same accounts for family history. Although it is very unlikely to find information about diabetes of other family members on their social network, relationships between them can be extracted from these networks. By questioning the users about diabetes in their families, a more detailed profile can be created of the user: a parent is of larger influence than a far relative. Finally, information about pregnancy diabetes can be shared through social networks. If, for example, information about pregnancy is found on the user’s network, by analyzing their posts, a more specific question about their pregnancy can be asked. As for weight, another mean of providing information is presented: a smart scaling device. These devices, such as the Fitbit1 https://www.fitbit.com/aria Aria and Withings smart body analyser2, are able to measure someone’s weight and wirelessly transmit it to an external application. Over all, depending on the scenario and bio-marker a sub-set of the following means of providing information, that are applicable, is presented: 1) Manually providing the data through an online form 2) Through Social Media 3) Through your Electronic Health Record (EHR) 4) Through smart devices In this type of question multiple options could be selected and a minimum of one option is required.

Frequency of Providing Information. For certain questions another follow-up question is the frequency of providing information. Certain risk factors, such as weight, diet & smoking behavior can frequently change and therefore have an important influence on the current risk of developing diabetes. So the frequency of sharing the information by the participants is also an important factor that should be measured in order to get a more detailed insight. For each mean of providing information question, a separate question for the frequency of sharing information might also be asked. So for example if both manually filling in an online form and through a smart scaling device are selected, two extra questions appeared: one question for each. This is done due to the fact that there could be a large difference between filling in an online form or transmit data automatically with a smart scaling device with regards to effort as well as cost. Manually providing the information requires more time than stepping on a scale that automatically transmits the data to the application, but the purchasing price of such a scaling device is also a factor to consider. Therefore, the participants are given the flexibility to accurately indicate this. Not every means of providing information question have a follow-up question for frequency. For example, length (as an adult), ethnicity and genome sequence are factors that do not change over time. Over all, depending on the means of providing information, scenario and bio-marker a sub-set of the following frequencies of proving information, that are applicable, is presented: 1) Only once, 2) Monthly, 3) Weekly, 4) Daily, 5) Whenever I feel like, and 6) Permanent Access. In this type of question multiple options could be selected.

Demographics. Questions related to each of the nine risk factors of diabetes used for this research and the associated questions are located in separate pages of the questionnaire. Besides these pages, two other pages are placed before these questions. The first page contained demographic questions, such as what is your sex, what is your age group and do you know someone with diabetes in order to investigate possible differences between demographic groups. For example the willingness to share information for diabetic research in people that know someone close to them diagnosed with diabetes compared to others is higher as they know how it is like to live with diabetes (Beckjord et al., 2011). The age groups are divided into three groups: youth (18-24 years), adult (25-64 years) and senior (65+ years), based on the Canadian age classification standard. No option has been provided for ages less than 18 as the minimum age of 18 is set as a rule for the questionnaire, in order for the participant him/her-self be able to decide on sharing personal information.

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1 https://www.fitbit.com/aria
5 Evaluation of the Survey

In order to develop a solid and sound questionnaire and in order to evaluate the compliance of the survey with the set rules discussed in section 4 an update cycle is used to improve the questionnaire. After each round of the cycle, the updated questionnaire’s compliance to the rules are re-verified. In the first step the questionnaire is tested by three experts. The purpose is to test if the setup is correct (e.g. to verify the questions, the question formulation, availability of answers) and to test the initial fitness to the set rules. Then a small pilot group of 10 participants are invited to participate in the questionnaire. The purpose of this phase is to verify the understandability of the questionnaire for a broader audience and to measure the required time to answer the questionnaires. The later is needed in order to verify if the questionnaire satisfied the set rules. The results indicate that in average the time needed to answer the questionnaire is 6 minutes, 19 seconds and the median is 5 minutes, 21 seconds. After further investigation it becomes clear that two participants took almost twice as long as the others due to external interruptions (e.g. phone call), making the average time longer than projected. After removing the outliers, the time needed to complete the questionnaire is satisfying (5 minutes, 42 seconds). Finally, every member of the pilot group is contacted and asked for feedback. Each question is discussed as well as the setup of the questionnaire. The feedback of the participants are then applied to the questionnaire. For example, it has been noted that the term genome sequence is not very clear, as well as pre-diabetes and pregnancy diabetes. In order to clarify the risk factors/bio-markers additional links to external web-pages are added with more information about genome sequences, pre-diabetes and pregnancy diabetes. Also the images of the scenarios are upgraded to better quality images. After these and other changes are applied, the questionnaire is then tested again.

6 Conducting the Survey

The survey is implemented using LimeSurvey\(^3\), an open source software for implementing complex surveys. LimeSurvey provides several features such as exportable paper-based version of the online questionnaire, follow up questions, multilingual support, and time-tracking. The PHP web application is installed on a private web server and made available. To ensure the privacy of the participant, secure connections are established using the SSL encryption protocol to prevent unwanted interception between the private server and the participants web browser. The start page provides the participant with information about the context of the questionnaire as well as an estimated completion time and information on how their information will be processed and handled, anonymous. Participants can also choose their preferred language: English or Dutch with the default set to English. When the participants are finished, they are presented with a thank you screen with a link to a page with information on diabetes type 2. This page is provided in order to create more awareness as well as inform the participant about diabetes mellitus type 2 and its risk factors. The survey is also advertised by means of email, social media and physical posters. The survey is conducted for two consecutive weeks and then closed. In total 116 responders have participated in the survey, 11 of which are incomplete. As such a total of 105 completed submissions are gathered resulting in a completion rate of 90.5%. The average answering time is 6 minutes, 46 seconds. This average response time is longer than projected (5 minutes), but further investigation shows some high response times (>25 minutes) that could indicate external interruptions in the survey process for some participants. The median however is 5 minutes and 22 seconds, which is satisfying regarding the rules set. Four participants out of the 105 complete results have only selected one scenario for all risk factors, while the intention is to select all applicable options. Since these results could act as outliers, they have been excluded from the analyse, as such reducing the number of valid responses to 101. Out of the valid responses, 39 participants are youth (18-24 years), 58 adults (25-64 years) and only 4 seniors (65+ years). Although the senior population is significantly lower in the sample group, this will not influence a smart wizard software for screening diabetes as the seniors are not in the target group for such a software. On the other hand 46 of the participants are male and 55 are female, suggesting an acceptable split between both genders. Although the participant are from 17 different nationalities, 74% of them have a dutch nationality. This is due to the fact the the research is conducted in the Netherlands. Finally our population is quite well distributed between different disciplines (23 from Computer & Information sciences, 24 from Biological & Health Sciences, 22 from Engineering, Physical & Social sciences and Psychology, and 32 from other educational backgrounds). While the level of education has shown not to influence the understanding of privacy, the field of study has been

\(^3\)https://www.limesurvey.org
Table 1: Overview of selection rates for frequency of providing information.

<table>
<thead>
<tr>
<th>Frequency</th>
<th>Selection Rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Whenever I feel like</td>
<td>38.5%</td>
</tr>
<tr>
<td>Only once</td>
<td>19.6%</td>
</tr>
<tr>
<td>Monthly</td>
<td>17.6%</td>
</tr>
<tr>
<td>Weekly</td>
<td>10.6%</td>
</tr>
<tr>
<td>Permanent Access</td>
<td>3.2%</td>
</tr>
<tr>
<td>Daily</td>
<td>2.9%</td>
</tr>
</tbody>
</table>

suggested to have such an influence (Ferreira et al., 2011). Other than this, the understanding of the importance of sharing this data for medical research might influence participants choice on sharing their information. The distributed between different disciplines in our study prevents biased results due to these factors.

7 STATISTICAL ANALYSIS AND USER SPECIFIC DATA COLLECTION FLOW

The statistical analysis shows that, as expected, an increasing amount of positive responses can be seen when the scenarios become more confidential. The diagnosed scenario is the most selected, with a 94.4% selection rate, followed by family related situation, (general) research and social chat scenarios with selection rates of 90.7%, 69.9%, and 53%, respectively. When looking at the means of providing information, manual submission of information is by far the most selected option with a selection rate of 28.9% followed by EHR, Smart Devices, Social Network with selection rates of 10.9%, 7.1%, and 1.9%, respectively. However, when only looking at means of providing the genome sequence, we can see that the selection rate for providing through EHR is 30.7% while manual submission is 29.8%. For all other risk factors/bio-markers, manual submission has been chosen substantially more. Finally, the frequency of providing information when applicable (weight, diet and smoking) are shown in Table 1. As visible, the option Whenever I feel like is by far the most selected frequency. Although for the risk factors weight and diet the second most selected frequency is Monthly, and for smoking, the second most selected frequency is Only once.

Using the above statistical analysis and by finding significant differences between different demographic groups, a user specific data collection flow model is designed using BPMN 2.0 for each scenario, that represents a smart wizard software for each screening phase. The significant differences are found used the binary logistic regression method. And if a significant difference is found, the Crosstabs method is used to discover the cause of the difference. A significance level of $p < 0.05$ is used to indicate significant differences for all methods. In order to demonstrate how these significant values are used to implement the model, one of the developed models (i.e. social chat representing the initial screening phase) will be discussed in detail. Each model consists of three lanes, two of which are the most important: the software lane and the user lane. The software lane represents the action preformed by the smart wizard software, such as asking a question. The user lane on the other hand represents the action by a participant in the screening process, such as providing an answer. Finally, the third lane represent external services that are invoked to retrieve information. The order in which the questions are asked in the model is based on the willingness of people to share their data related to a bio-marker. Table 2 demonstrates the distribution in which the respondents are willing to share information in social chat context. As visible most of the participants are willing to provide their age, while the least are willing to provide their genome sequence. This order is used to prevent offending users of the software, by asking for data that are not likely to be share by them, and to keep the user engagement with the wizard to its maximum.

Now that the order in which questions are asked by the software has been set, the focus lies on what can and cannot be asked to the users regarding a higher chance of offending them. To achieve this as stated in the method, a binary logistic regression has been conducted. If a significant result was found, a crosstabs method was used to get insight on what caused the significant difference. Our findings suggest that women are significantly less likely to provide information about their age, height and weight compared to men. On the other hand our finding also suggest that non-Dutch (minorities) are significantly less likely to provide information about their age and height. These significant differences are modelled into the smart wizard software model. There-
fore, the software asks the user for his/her sex as well as nationality first in order to decide what questions should be presented further. The complete model for the social chat scenario is illustrated in the BPMN notation\(^4\). The first two questions ask about the sex and nationality. After which the age is asked about. However, due to the identified significances the model is adjusted. The same approach is followed for height, weight and pre-/pregnancy diabetes.

Regarding the means of providing information, it is important to notice that all information have to be provided manually with the exception of genome sequence. Since there is almost no significance difference between manual submission and EHR the decision has been made to provide the user with both options. A XOR statement enables the user to select one of the options. If the user selects the option to share it through his/her electronic health record, a request to an external service is made, i.e. the service that holds the data of the electronic health record.

Finally, the frequency by which data can be gathered is also implemented in the model. As discussed before and visible in Table 1, the option to share information whenever the user feels like is the most selected option. For both diet and weight the second most selected option is monthly and therefore a reminder is modelled for these factors. For these cases the user is send a monthly reminder via a notification (e.g phone notification or email), stating that the user can update its information if he or she feels like doing so. It is important to state that at each point the user has the ability to skip every question.

8 DISCUSSION

One should have in mind that people are not always completely honest when asked about privacy related matters and in real-life might act differently. This might jeopardize the results of this research, as such on one hand, we have tried our best not to reveal the intention of the questionnaire to reduce any pre-judgement and perception that might cause this phenomenon and on the other hand, we observe the participants tendency to being truthful, by their response to situation questions addressed in section 7. Another possible challenge with our approach rises when the user is not asked to provide bio-marker information for some of risk factors. For example BMI for obesity in women and non-Dutch users in the model of the social chat cannot be calculated. However, BMI is a very important factor to know, since overweight is the primary risk factor for diabetes type 2 for both adults (Hartemink et al., 2006) and children (Wei et al., 2003). This becomes further clear when looking into a study (Baan et al., 1999) that has investigated what data is essentially required to identify patients at a greater risk of developing diabetes type 2. This study created three risk prediction models. The first model is based on data gathered in files of a general practitioner, such as age, sex and absence of obesity. The second model used additional information by asking questions about family history and smoking. The third model incorporated medical data, such as diastolic blood pressure and systolic blood pressure. The study has concluded that while the first and second models generate similar results, adding the risk factors in the third model is not useful, and the extra medical data used in the third model has no additive predictive value. At the end researchers have recommend the first model, since it uses less information that is usually available in the patient specific notes of a general practitioner. Even when looking at the minimal model still obesity, as a risk factor, plays a critical role and as such the bio-marker BMI is critical in properly assessing the risk of developing diabetes type 2. A possible solution can be to estimate critical bio-markers such as BMI for patients using knowledge-based and learning-based approaches (Khan et al., 2012) to fill in gaps where information is missing.

9 CONCLUSION AND FUTURE WORK

The aim of this research is to achieve a model for user specific data collection, using a smart wizard software that would ultimately provide users with an indication of their current risk level, when also considering socio-economical aspects. As a first step in this process, we have created four models (for different types of possible software scenarios) that can be used to create a user specific software wizard to gather data related to diabetes type 2. A survey is conducted to measure the willingness of users to share data about different risk factor. Four scenarios are used to distinguish possible differences in the willingness to share information in different phases of screening for diabetes type 2. The users are also asked about the preferred means of sharing the information and, if applicable, the frequency in which they are willing to share this information. Future work can use the method proposed in this research to develop similar data collection models for other diseases. Another further research can be conducted with larger and more di-
verse populations to investigate possible differences between regions and countries. Also, once the wizard is developed, evaluation of the approach can be preformed using A/B testing and measuring parameters such as the dropout rate.

REFERENCES


