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A dynamic personal medical record improvement: Pilot study for diabetes self-management in Serbia

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Abstract. In this study, we investigate the potential for improving the control of patient's health status, by giving them a specific role in the management of their condition. In particular, we study the aspect of patient cooperation in facilitating the self-control of their health status, by combining relevant medical data with environment data, using telecom and IT services. The main question is related to patients' willingness to keep an updated personal medical record, making it dynamic, and to share the record with other health care institutions and their staff in case of travelling. The hypothesis is that regular feedback to the patient from the dynamic medical record would improve the life style, diet and correct doses of medicines for controlling the health condition.
The study was conducted on 62 randomly selected individuals with diabetes, from the medical practice database in Belgrade, Serbia. The results showed that 56% of participants preferred SMS as a mean of communication, followed by phone calls (18%), and email (16%). Also, the study showed that 68% of participants were willing to allow access to their medical record, whilst the rest of participants were worried about data protection issues. The results of this study showed current poor control of patient condition, regardless of the fact that regular advice was given by the family doctor on a three months basis.

Keywords. diabetes, self-management, medical record, travel, SMS.

1. Introduction

Managing diabetes, as well as other chronic conditions, amongst other factors, is highly dependent on self-management of the condition. Numerous studies concluded that efforts should be focused on behavioral therapy (i.e. diet, activity level, medical adherence, regular assessments by specialists) assisted by

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technology, through sending reminders or encouragement (educational messages) to patients (1).

Telecom and IT services are already in use for tracking and improving some conditions: telephone services for dementia (2), education about epilepsy (3), diabetes self-management mobile phone applications (4), medical data collection (16), personal health record (5), and reminders about regular appointments with specialists (6).

Acematsu et al (10) studied the influence of tele-care systems on the length of the hospital stay of chronic patients. They showed overall stay in the hospital per incidence was 8.7 days per year longer for patients with a chronic condition in comparison to patients without a chronic condition. The research showed that tele-care system used (daily reports sent to hospital including measurements of blood pressure, ECG, and blood oxygen) decreased the number of hospital days for chronic patients by 3.1 days. The study by Darkins et al (11) shows similar results.

Cassimatis and Kavanagh (12) reviewed the effect of behavioural tele-health interventions on glycemic control and diabetes self-management by assessing the following parameters: diet, physical activity, blood glucose monitoring and medication adherence. The study was conducted on diabetic patients in Australia and showed that the majority of diabetes patients remain poorly controlled (HbA1c >=8%) with the conclusion that effective and accessible Type2 diabetes self-management support was required. Schreir et al (13) study assessed differences in diabetes management by using web-based applications in comparison to mobile-based applications. The study conclusion was that the adherence during the first year showed no significant difference between the two methods. A systematic review by Deglise et al (14) showed an increase in using mobile phones for health purposes (m-health). However, the benefits of m-health applications are currently seen only from the work done in developed countries. Siriwardena et al (15) showed that behavioral therapy was used as a key intervention in improving chronic condition, where HbA1c was the primary outcome measure and in some studies fasting blood sugar, postprandial blood sugar, blood pressure, body mass index and lipid levels were secondary outcome measures.

Building up on the known pool of the results and methodologies, we created two protocols: protocol of collecting data for patients with diabetes and statistical analysis of the data, as well as a protocol of discussing with them the condition and the way of improving self-management of their health condition. The aim of this article is to show the importance of collecting self-management data in the patient medical record and using the feedback, created by data mining techniques, in adopting the life style that would lead to better quality of life. This is based on two hypotheses:

1) Introducing telecom and IT services for managing chronic conditions by two-way communication between patients and the clinic may significantly improve the patient medical record by introducing dynamic data feeds (daily glycemic measures, environmental data – air temperature, air humidity, etc.), in addition to static data (gender, DOB) – entered in the medical record once, and semi-dynamic data feeds (BMI) updated on a three months basis during regular checkups with the doctor, and

2) The existence of a dynamic medical record may help improve the quality of medical help given in remote/travel locations. We believe that having larger and up to date health parameter data sets will initiate better control of the condition, provide additional information for diagnostics and delay complications.

2. Objective

The purpose of this study was to suggest that larger data sets collected from patients using different methods of communication may improve their health condition control and delay complications, and may improve medical help given when the patient is not at home location (by providing necessary data sets for clinicians at remote locations).

We conducted a pilot study on a sample of Serbian diabetic patients in order to assess the overall state of current diabetes control in this region, and to assess patients' willingness to participate in technology assisted diabetes care. We created a questionnaire, for the purpose of this study, that reflects the specifics of the region studied, which consists of the following main parts: questions about patient life style, self-care, willingness to use technology in managing self-care, and willingness to allow access to the personal medical record whilst traveling.

The study is focused on the Balkan region (Serbia), as we believe that specifics of the region and penetration of technology in the local markets have a significant effect on creating a dynamic health record. We are suggesting that presence and accessibility of different technologies and differences in medical policies and practices have to be carefully studied when creating a dynamic health record. Furthermore, we are suggesting a dynamic health record protocol that is technology agnostic, but we are aware that user interfaces may be designed using different technologies depending on the region. Thus, we are interested in the user interface with the technology service being SMS, phone call and e-mail in the Balkan region, but we are also suggesting the mobile phone application that would accompany the same concept in developed countries.

3. Methods

The environment to support the enhanced data sharing mechanism should, in our opinion, include the following participants: patient, family doctor, specialist clinician, medical insurance company, and travel location clinic.

3.1. Description of the proposed dynamic medical data record

We propose an enhanced data gathering and data flow when the patient is at home location and suggest that the dynamic medical data record should include the following additional data on a daily basis: vital health parameters uploaded to the medical record so the trending can be tracked between the regular (usually three months) checkups. The patient provides the vital data statistics (GL – Glucose measurements, BP- Blood Pressure, Medication adherence confirmation, Body

temperature, Activity Level, Stress Level). The patient also receives regular reminders about the appointments he/she needs to make on a regular basis, plus additional appointments that are triggered by trending analysis of the data submitted. The medical record is also fed by the meteorological data based on the patient location. The detailed proposed data flow between the patient and the dynamic medical record is presented in Figure 1.

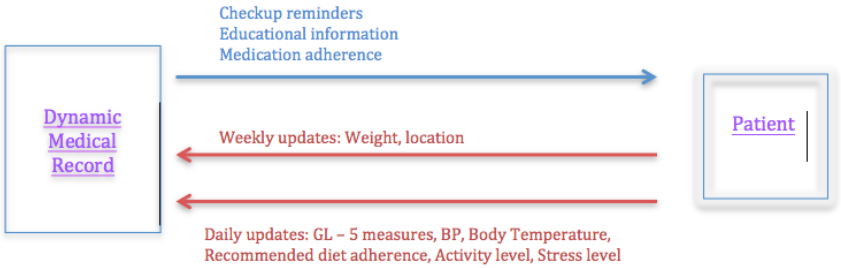

Figure 1. Dynamic Medical Record: Collects weekly and daily updates from the patients and sends feedback information based on the data trending received.

A possible user interface for patients with the ability to use a smart phone is suggested in Figure 2.

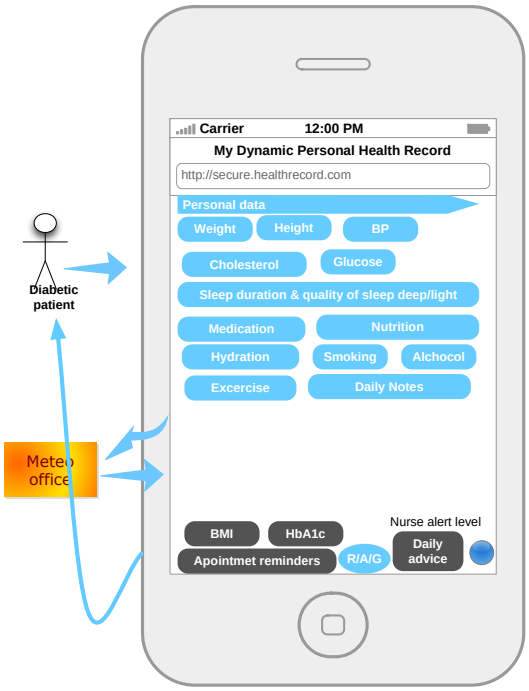

Figure 2. Possible smart phone user interface for a dynamic medical record

The detailed data flow in our suggested dynamic medical record eco system is shown in Figure 3. When the patient is travelling (away from home location), the clinic at travel location and travel insurance are included in the communication system.

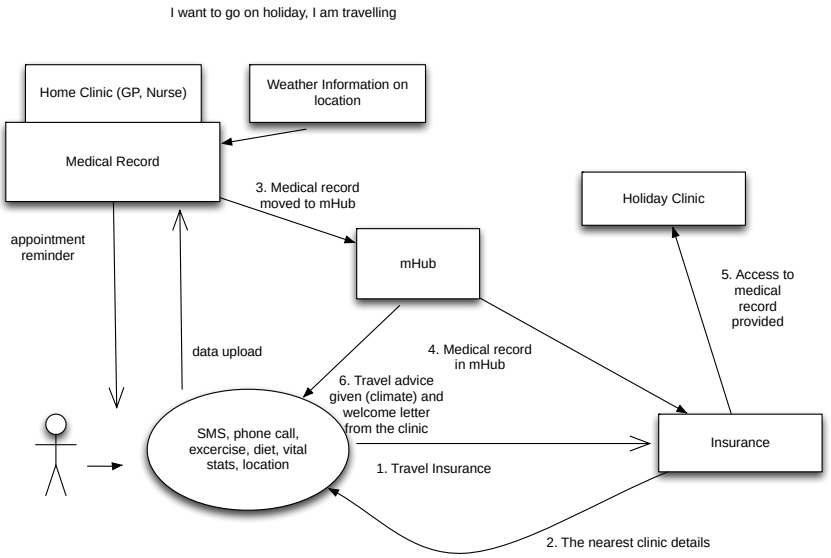

Figure 3. Dynamic Medical record eco system - Data flow when patient is at home location and away from home.

Figure 3 explains that the patient is in control of his/her medical record by providing regular updates of health parameters, using any of the technologies available for such an activity. We suggested SMS, email or telephone call, whilst the latest technologies, including wearable technologies, can possibly in the future feed the data into the medical record, even without any patient interaction to trigger the data feeding process.

We also believe that the medical record fed with the regular updates about weather conditions, based on the location of the patient, will give significant information to clinicians on how the patient is responding to certain medications, for example in changed environment conditions.

When traveling, the patient will update their medical record about this intention, purchase the necessary travel medical insurance, and the subset of necessary data will be updated to mHub (medical Hub). The medical insurance company will suggest clinics, which are covered by patient insurance in the area of travel, and the patient will be informed of their location, should medical help be needed while away. The mHub will inform the insurance company of the mHub record availability, and the insurance will provide access to the medical record to the suggested holiday clinics.

We suggest that sharing personal medical data whilst changing the place of residence (due to travel) can significantly improve help given if needed in the place of travel, show changes in the medical record due to different environments, possibly reduce the medical insurance premium, and improve quality of travel.

In case that medical help is needed whilst away from home location (Figure 4), the patient will be able to contact the clinic, being that data have already been provided to him/her prior to travel. The medical clinic will be able to access the mHub to retrieve the necessary patient medical record and provide targeted treatment. The mHub record will show the remote clinic's patient medical record, including history of the illness, other illnesses present in addition to the chronic condition, medications prescribed at the home clinic, and differences in the environment factors between home location and travel location. With all the enhanced information about the patient available and at hand, the clinicians at the travel location would be able to provide more targeted and beneficial treatment. The mHub record is then updated, the patient medical record is updated, and the insurance company informed about details of the treatment given.

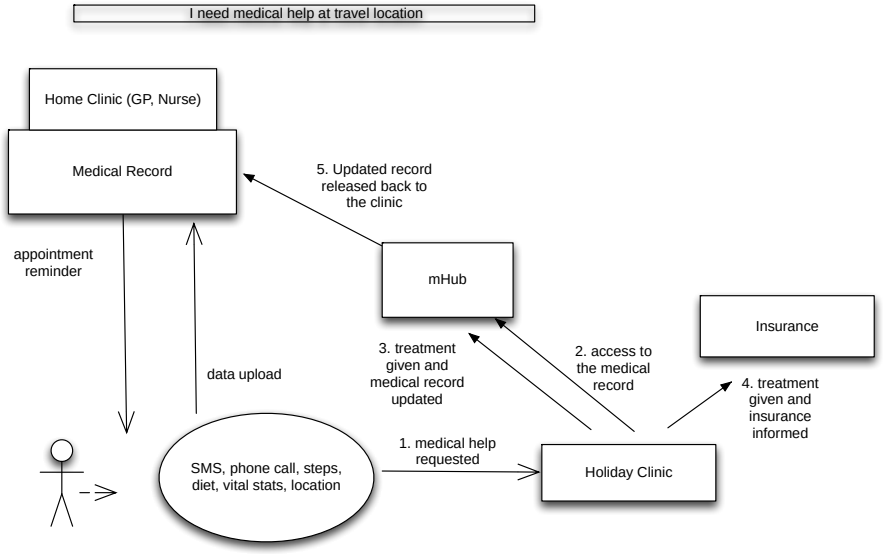

Figure 4. Dynamic medical record is made available to Holiday clinic and Medical Insurance in case of travel (Medical help is needed)

In case that medical help is not needed at the travel location, the medical record from mHub will send a notification to the home clinic medical record, and the insurance company will receive a notification of ending of the insurance period with no medical help required. (Fig.5)

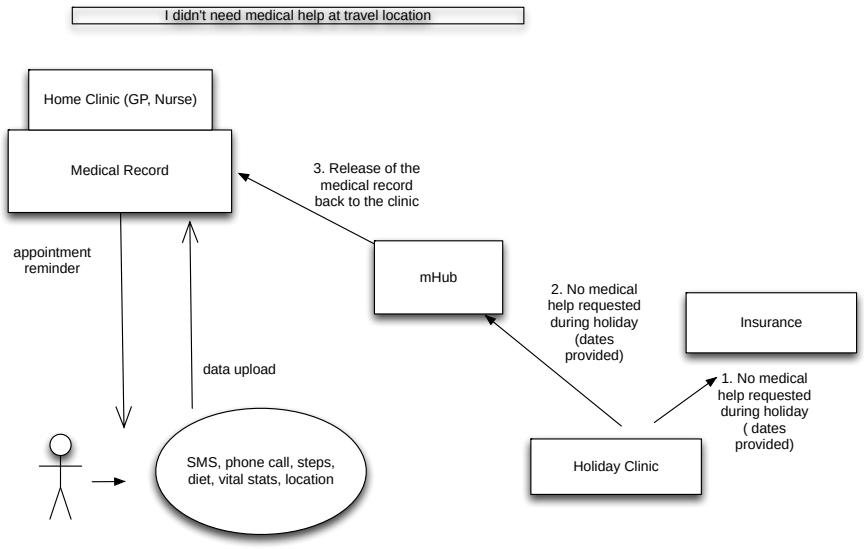

Figure 5. Dynamic medical record is made available to Holiday clinic and Medical Insurance in case of travel (Medical help was not needed)

There are many challenges facing cross-country medical record sharing, mainly due to lack of unified policies across countries and different penetration of Electronic Health Record (EHR) between developed and developing countries (17).

We believe that subset of patient data from the Medical Record (either paper based or EHR) should be available for patients to access and share with clinics in the countries they are traveling to (mHub).

This model would truly enable patient centered care, where patient is able to choose whether or not he/she is willing to share the medical record data, and to what level of granularity he/she wants to populate the medical record (daily feeds, weekly feeds, occasional updates).

3.2. Pilot Study

In order to test the described concepts, we designed a pilot study that would consider all of the mentioned aspects of managing diabetes at home location and in a changed environment, and patients' willingness to implement the suggested improvement methods.

3.3. Participants

The study was performed at the Clinical Medical Center 'Palilula', Belgrade, Serbia, during a four months period. Seventy patients with diabetes were randomly selected from the database of the medical clinic record. The clinic is one of 25 clinics covering the urban area of central Belgrade, Serbia. The participants

in the study were regular patients of the selected medical clinic, living in close proximity of the clinic, and subsequently exposed to the same environmental factors (number of green markets, number of parks and sports facilities, pollution levels) and were diagnosed with diabetes.

3.4. Environment

Let us here briefly give the characteristics of the area where the study took place. The study was conducted in the urban area of Belgrade, Serbia populated with 136,478 people (according to the census 2010), 46% male and 54% female. The level of computer literacy in this group shows the following structure: 50% of people are computer literate, 13% are partially computer literate – can perform basic skills like email reading/writing, and 37% are computer illiterate persons - neither own nor are able to use a computer.

3.5. Study protocol

The study protocol is depicted in Figure 6. When patients came to their regular appointments, they were asked whether they would be willing to participate in the study and details of the study were explained to them. In case of acceptance, the patients were asked to perform the required laboratory test prior the next appointment and bring the results of the tests (HbA1c, non-fasting glucose level, cholesterol level and triglycerides level). The following consultation included administering the assessment questionnaire to the participants, created for the purpose of this study by clinicians and a psychologist (for full details of the questionnaire, please see Appendix - Supplementary Material Part1).

Figure 6. Study protocol

The patients signed the consent form when the family doctor explained the study details to them. The discussion about the laboratory results and self-management of the condition, followed by the questionnaire, was performed by family doctors who recorded the responses and explained questions that required further clarifications.

4. Results

4.1. Participants profile

Out of the 70 randomly selected patients, 63 patients accepted to participate in the study and one patient did not perform the required laboratory test prior the consultation, so the total number of valid entries was 62. The gender distribution of participants was the following: Men 55%, Women 45%, and the age distribution is shown in Figure 7.

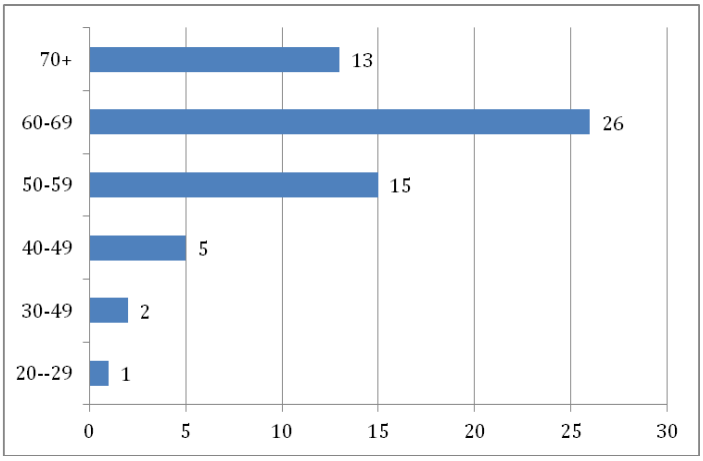

Figure 7. Age distribution of the study participants

Out of 62 participating patients, 8% were diagnosed with Diabetes Type 1 – E10 (18) and 92% with diabetes Type 2 – E11 (18).

The study group consisted of 58% patients with diabetes diagnosed 10 or fewer years ago and 42% with diabetes registered more than 10 years ago.

All participants in the study allowed access to their medical record in order to collect details of other illnesses present in addition to diabetes (E10 or E11, ICD-10 code, 2010). The analysis shows prevalence of hypertension (Figure 8), with 75% of the patients with registered E11 (Diabetes Type 2) and 20% of patients with registered E10 (Diabetes Type 1) suffering from hypertension (i10, ICD 10, 2010). Other illnesses present in addition to diabetes are presented in the Appendix - Supplementary material Part 2.

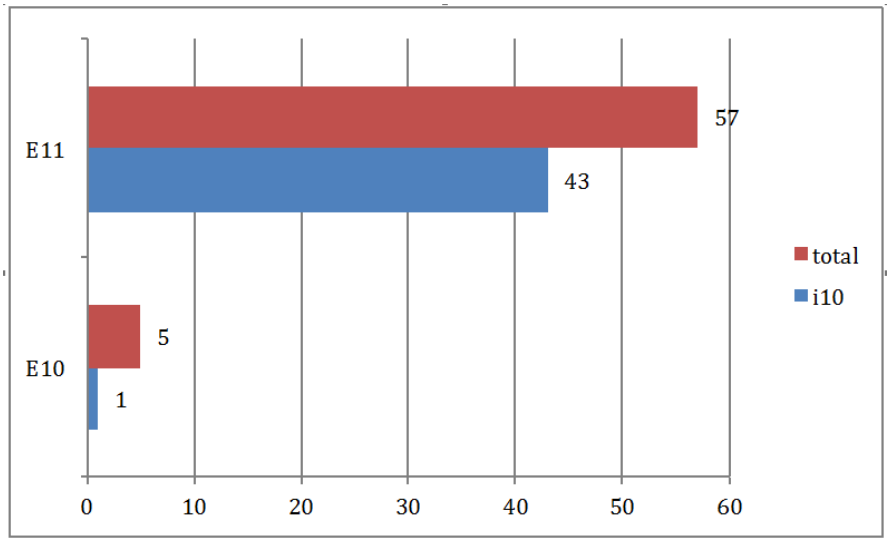

Figure 8. Distribution of diabetic patients suffering from hypertension

Diabetes complications were present in 35% of patients; out of which 77% had diabetes registered more than 10 years ago.

18 % of the participants use alternative medicine to complement control of their condition.

4.2. Lab analysis

As part of the study, all participants were asked to perform the following lab analysis: HbA1c, non-fasting glucose level, total cholesterol level, and level of triglycerides. The results of the analysis showed poorly controlled condition:

- 37% patients have higher values than recommended for HbA1c
- 19% patients have higher values of non-fasting glucose than recommended
- 60% patients have higher than recommended total cholesterol level
- 40% patients have higher than recommended levels of triglycerides

4.3. Questionnaire results

4.3.1. Life style questionnaire results

Smoking. 29% of the study participants are smokers. Out of 44 non-smokers, 18 have quit smoking in the last 5years, with 78% male and 22 % female gender ratio in this group; whilst the rest of the group (26) has never smoked.

Alcohol consumption. The results showed that 42% of participants never consume alcohol, 35% of participants consume alcohol 2-3 times per month, followed by 13% of participants with alcohol consumption 2-3 times per week, and 10% of participants with every day alcohol consumption.

Physical Activity. The results showed that 45% of participants are active, 26% not active/sedentary and 29% are people with moderate activity level (walking at least 30 minutes a day).

Shopping for food and healthy diet. It is important to note that a habit of the assessed area is that the food shopping is still done mainly at the green markets with fresh produce. The food preparation prevalence is cooking at home, although the combination of fast food and home cooking is showing signs of increasing, especially in the age groups below 40.

The results show that 70% of participants go food shopping by foot to the nearest green market or grocery store, 24% go by car, and 6% of participants use public transportation.

When asked about the diet regimen they follow, and based on the recommendations given by their doctor, 27% of participants said that they follow the recommended diet, 27% of participants rarely do so, and 46% occasionally.

76% of the study participants prepare their food at home or they have someone prepare it for them, and 14% eat fast food in addition to cooking at home.

4.3.2. Diabetes self-management questionnaire results

When asked about maintaining a food diary and performing comparisons with the measured blood glucose levels, 34% responded that they have a food diary and perform the comparisons. However, all of the study participants believe that the regular diary comparisons with glucose levels would improve their control of diabetes.

Frequency of blood glucose testing. 42% of participant test their blood glucose levels once a week, followed by 16% who test 2-3 times a week, and with only 3% of the participants taking measurements a couple of times a day. The remaining patients do not take measurements. When asked why the measurements are so infrequent (in case measurement is taken less than once daily), the main reasons highlighted by the study participants were the following: unavailable/too expensive glucose meter and testing strips (42%), lack of time (21%), and consideration that the measurement is not important (37%).

4.3.3. Willingness to use technology in diabetes self-management

Reminders. The participants were asked whether they would be willing to receive reminders about their specialist appointments, taking glucose measurements, and receiving general advice about their condition. All of the participants stated that they believe that reminders would help them control their condition better, with only 3% stating that they would not want to receive regular communication from their clinic.

Participants were then asked what would be their preferred method of communication with the clinic concerning these reminders and advice (email, SMS or telephone call) and were allowed to choose more than one communication method. The result shows 56% of the participants favouring SMS as the communication method, followed by telephone call and email, with similar preference.

4.3.4. Willingness to share personal medical record with other clinic's other than home clinic and/or medical insurance

Travel planning. When planning to travel, 40% of the participants do not consult with their GP on adapting their medicine intake, based on the change in climate, change in dietary regimen or level of activities undertaken.

When asked whether they would want to receive contact information of the nearest clinic in the place of travel in case any medical help is needed, 90% of the participants responded positively.

However, only 68% of the study participants responded positively to willingly sharing their medical record with the clinic in the place of travel, whilst 32% of participants were reluctant to share their medical data due to data protection.

5. Discussion

The study showed a number of factors influencing quality of diabetes self-management (socio-economic factors, computer literacy, education level about diabetes, other conditions present in addition to diabetes, life style). Although regular three months check-ups appointment with the family doctor are provided, the level of diabetes control remains poor based on the performed lab test analysis. The reason for this might be the fact that patients are not provided with regular feedback in-between the appointments, in order to help them manage their condition better. We suggest that any technology-assisted feedback would be useful in improving self-management. The study we performed suggested that SMS would be preferred technology to assist in this process.

Patients also confirmed their willingness to receive information about their medication adjustments and life-style adjustments when travelling. Larger study should be conducted on showing benefits of such a method, where patients are populating their medical record with the data, both at home location and travel location. All study participants also confirmed that they would be keen to receive information about the nearest clinic where they can seek medical help should they need it. However, 68% of participants said that in additional to receiving that information, they would be willing to share their medical record with the clinic at travel location and/or travel medical insurance provider due to data protection sensitivity. We believe that this can be improved by offering secure data transfer between the clinics and by providing patient education about the methods.

By creating mHub (subset of medical record data) for each patient whilst traveling, there would be multiple benefits: 1) patient – by populating medical record data, patient will be able to receive feedback about trending in managing diabetes, possible influence on self- management of changed life style, diet or climate change when travelling, 2) clinician (home and travel location) – bigger data set about patient will allow better diagnostic, reduce costs associated with complications due to close trend monitoring 3) medical insurance – comprehensive and tailored medical insurance products can be calculated on a case by case basis based on bigger data sets available in medical record.

6. Conclusion

This pilot study highlighted some important aspects of diabetes self-management in Serbia, based on the specific characteristics of the local environment (diet, fitness level, life style, economic conditions, availability of health care, awareness of the importance of self-care in managing the condition, computer literacy). The preference of using SMS as a method of communication with the clinic for the majority of participants (reminders and advice) may be explained by a broader access to SMS than to e-mail, which is closely linked to the computer literacy level in the area (50%), and to non-existent or poor access to free Wi-Fi at the place of travel. When comparing to the landline calls, SMS may be the preferred method because of an increasing penetration of mobile phones and their usage in Serbia, as well as because SMS may be considered as one-way communication if patients are not requested to respond to the messages.

The fact that participants are not taking regular blood glucose level measurements at least once daily, as recommended, shows a significant obstacle in managing diabetes, with over 40% of participants explaining that the reason for this is that they simply do not have the means to do so, due to unavailability of the glucose testing strips that are too expensive. This socio-economic factor may be a major blocker in establishing technology-assisted self-management of diabetes in Serbia. The other participant responses concerning this issue ('too busy', 'that is not so important') are less of an obstacle and may be changed significantly through educational SMS messages sent to participants.

The possible negative impact on patient health due to changes of the family doctor/specialist, or patient's change of location (travel) may also be improved by the medical record sharing between clinics and travel insurance providers. 68 % of participants showed their willingness to share their medical data with another clinic, which is a promising factor in improving self-management.

We propose different models of communication between the patient, home clinic, clinic at travel location, and travel insurance, in different conditions (medical help needed or not needed). The models proposed are currently not available on the market and our hypothesis is that their presence would significantly improve management of chronic conditions by better self-control in changed conditions, and by better diagnostics due to availability of larger data sets about the patient.

This pilot study may be used as a starting point for larger studies, not only related to diabetes but other chronic conditions as well, by linking the SMS messages (preferred communication method) to patients' medical records and sharing the medical records with other clinics. In the future work, we plan to conduct a larger randomized controlled study, where the patients would be tracked in their home location and their travel location, and data would be collected from both locations to show differences in health responses to different environment and life style changes.

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The authors would like to declare that there is no conflict of interest concerning the publication of this article.

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Appendix

Supplementary material – Part1

Table 1. Sample questionnaire

Diabetes self-management improvement study, Belgrade, Serbia, 2014

Assessment Questionnaire

Patient information

First name:

Surname:

Gender: □ Female □ Male

DOB:

Age : □ 40-49 □ 50-59 □ 60-69 □ 70+

Home address:

Height (cm):

Weight (kg):

BMI:

Waist (cm):

Blood pressure (Systolic/Diastolic):

Cholesterol (LDL, HDL, Total):

How long ago was diabetes diagnosed:

Any diabetes related complications:

Other illnesses:

Family History

Family history of any of the following illnesses (by close family member):

□ Diabetes (Type 1) – medical code E10

□ Diabetes (Type 2) – medical code E11

□ Heart disease

Life style

Smoking

Do you smoke?

□ Yes

□ No

If yes, how many cigarettes a day?

If not:

□ Never smoked

□ Stopped smoking less than 5 years ago

□ Stopped smoking more than 5 years ago

Alcohol consumption

How frequently do you consume alcoholic beverages?

□ Never

□ Once a month

□ 2-4 times a month

□ 2-3 times a week

□ 4+ times a week

How many units of alcohol do you consume per occasion:

□ 1-2 □ 3-4 □ 5-6 □ 7-9 □ 10+

Have you consumed 6 units (women)/8 units (men) during one occasion in the last 12 months?

□ Never

□ Occasionally

□ Once a month

□ Weekly

□ Daily

Fitness level

Would you describe yourself as:

□ Active

□ Moderately active

□ Sedentary

How many times a week do you join an organized fitness activity :

□ Never

□ Once Weekly

□ Few times per week

□ Every day

When shopping for food, what type of transport do you use:

□ Walking

□ Public transportation

□ Car

Nutrition

Do you eat healthy food?

□ Yes

□ Mainly

□ Occasionally

□ No

What type of food is prevalent in your diet?

□ Home-cooked food (I prepare or family member prepares it for me)

□ Fast food (pre- packed, ready made food)

□ Combination of fast food and home-cooked food

Do you compare your food diary and blood glucose measurements?

□ Yes

□ No

Do you believe that regular advice about healthy nutrition would help you control diabetes?

□ Yes

□ No

Self Control

How frequently do you test your blood glucose levels?

□ Three or more times/day

□ Once a day

□ Few times per week

□ Once a week

□ Once a month

□ Rarely

If you test your blood glucose levels less than once a day, what is the main reason for that:

□ I am busy

□ I don't have enough testing strips (too expensive)

□ I don't think that is important

□ Something else: _______

How frequently do you check your HbA1c :

□ Once in three months

□ Once in six months

□ Once a year

□ Rarely

□ Never

Do you visit your doctor who is helping you manage your condition on a regular basis?

□ Yes

□ No

Would you be interested to receive regular reminders about glucose control, nutrition, and physical activities via SMS/phone/email?

□ Yes

□ No

What type of communication would you prefer?

□ Phone call

□ SMS

□ Email

Travel

When planning your travel, do you discuss adaptations of your medicine doses and life style changes due to changes in the environment with your doctor?

□ Yes

□ No

Would you be interested to get contact details of the nearest clinic at the travel locations, should you need any medical help?

□ yes

□ No

If yes, would you be willing to share your medical record data with the travel clinic, so that medical help can be the most relevant should you need it?

□ Yes

□ No

What would be, in your opinion, the best way to improve your diabetes self control:

□ More frequent visits to the doctor

□ Reminders (SMS, phone call, email)

□ Better nutrition (Healthy food choices)

□ Increased physical activity/ improved fitness level

□ Other: _____

Supplementary material – Part 2

Table 2. Other illnesses present in addition to diabetes (with ICD-10 version 2010 medical codes)

Code	Medical condition	Number of patients in the study affected
C20	Malignant neoplasm of rectum	1
C73	Malignant neoplasm of thyroid gland	1
D21	Other benign neoplasms of connective and other soft tissue	2
E03	Congenital hypothyroidism with diffuse goiter	3
E06	Acute thyroiditis	2
E66	Obesity due to excess calories	1
E78	Pure hypercholesterolaemia	11
F32	Mild depressive episode	4
G45	Transient ischemic attack	2
H25	Senile cataract	4
H40	Glaucoma	2
I20	Angina pectoris	4
I21	Acute myocardial infarction	1
I24	Coronary thrombosis	3
I32	Pericarditis	1
I63	Cerebral infarction	5
I70	Arthrosclerosis	1
J44	Chronic obstructive pulmonary disease	1
J45	Asthma	2
K21	Gastro-esophageal reflux disease	1
K80	Calculus of gallbladder	1
K86	Alcohol-induced chronic pancreatitis	1
L40	Psoriasis vulgaris	3
M05	Seropositive rheumatoid arthritis	1
M10	Gout	5
M17	Gonarthrosis [arthrosis of knee]	1
M32	Systemic lupus erythematous	1
N18	Chronic kidney disease	2
N20	Calculus of kidney and ureter	1
N40	Hyperplasia of prostate	3
Z95	Presence of cardiac and vascular implants and grafts	4