SPECIAL ARTICLE
ΕΙΔΙΚΟ ΑΡΘΡΟ

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Introduction to a new online platform
for collecting experimental data

Current technological advances offer great opportunities for the development of tools that can assist medical research without devaluing the importance of the patient-researcher relationship. medicalresearch.gr is an online platform that can help with remote, electronic data collection. It allows researchers to easily design their experiments, manage participants, administer automatically rated questionnaires and tasks and organize all collected data in a database ready for analysis. Given the various features and functions of the platform, as well as the several disadvantages of the in-person non-automated way of data collection, we believe that this is a valuable tool that will greatly facilitate the experimental process and improve its quality.

V. Mantas

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*First Department of Psychiatry,
National and Kapodistrian University
of Athens, Athens, Greece*

medicalresearch.gr:
Εισαγωγή σε μια διαδικτυακή
εφαρμογή για τη συλλογή
ερευνητικών δεδομένων

Περίληψη στο τέλος του άρθρου

1. INTRODUCTION

Today, the majority of information exchange happens remotely and more than ever before, computers and access to the internet are considered necessary and are widely available. This advancement and broad availability of technological resources offers the possibility to develop methods and tools that could greatly improve and even revolutionize research. In most research fields, this is already the case, mainly when data processing and analysis are considered. Online statistical tools, machine learning and data simulations are only a few of the many examples of readily available methods and tools that have been developed and made easily accessible to most researchers as a result of the advances made in technology and computer science.

Data management and collection, however, especially in medical research, where patient populations are concerned, have not yet equally profited from these developments.[1] The explanation for this could be two-fold. On one hand, the direct interaction between the patients and the medical doctors or researchers is considered paramount for the medical practice and relevant data collection. As a result, means that could threaten to substitute this direct exchange with remote interactions are met with great scepticism by the research community and the volunteers. Given that the importance of the patient-researcher relation is not devalued, the development of such tools should be promoted as this can be very beneficial (see "Discussion"). On the other hand, specialized tools for medical research data collection are currently greatly lacking.[2] Even if a researcher decided to collect data for an experiment remotely, they would probably end up emailing the participants, exchanging documents with them or employing other practices that do not at all profit from the current technological possibilities.

In the present study, we introduce a scientific tool, an online platform for medical research data collection. The platform, medicalresearch.gr, allows for the remote, electronic collection of volunteer data, including questionnaires and tasks, for their automated rating, and the organization of the collected data in a database that is ready for analysis. In the paragraphs that follow, the main functions of our platform will be presented through an example that would allow us to demonstrate some of the unique features that the platform offers to researchers and volunteers. We will not make an exhaustive description of all the functions of the platform as these could be found in the electronic manual that is accessible online (https://medicalresearch.gr/manual.php).

2. DESCRIPTION OF THE PLATFORM FEATURES

2.1. Access and subscription

The online platform is available at the internet address https://medicalresearch.gr. It can be accessed using a web browser that can execute JavaScript programming language, a requirement that is fulfilled by all the currently available and commonly used web browsers. This makes the platform highly portable, as it allows it to be available and usable from any device that has an operational system and is connected to the internet. In order to use the platform, individuals need to subscribe by providing an e-mail address and a password. After subscription, individuals can use the platform either as researchers or volunteers.

2.2. Researchers

For the purpose of this article, let us assume that a researcher wishes to conduct an experiment in a group of volunteers that have a specific characteristic, for example participants with depression diagnosis, and compare their performance to a group of healthy controls. The experimen-

tal procedure involves two questionnaires and a task, and as for the experimental design, each volunteer in both groups will answer both questionnaires in a randomized order followed by the task. The data collection for this experiment has two stages, both including the same aforementioned design but separated by a seven-day period. Below we will describe how our platform could be used to design and set-up the experiment, invite volunteers for participation, and collect the experimental data.

2.3. Experimental design

The first step to designing an experiment using the platform would be to create the two questionnaires and the task. Each questionnaire and task is saved in a personal repository and is always accessible for future experiments. In the questionnaires, each question is formatted separately, and according to the type of answer that corresponds to each question. The researcher can select between a text, number, date or multiple choice answer type. The questionnaires can be divided into specific sections and within each questionnaire, there is the option to randomize the order of administration of all or specific questions (fig. 1). There
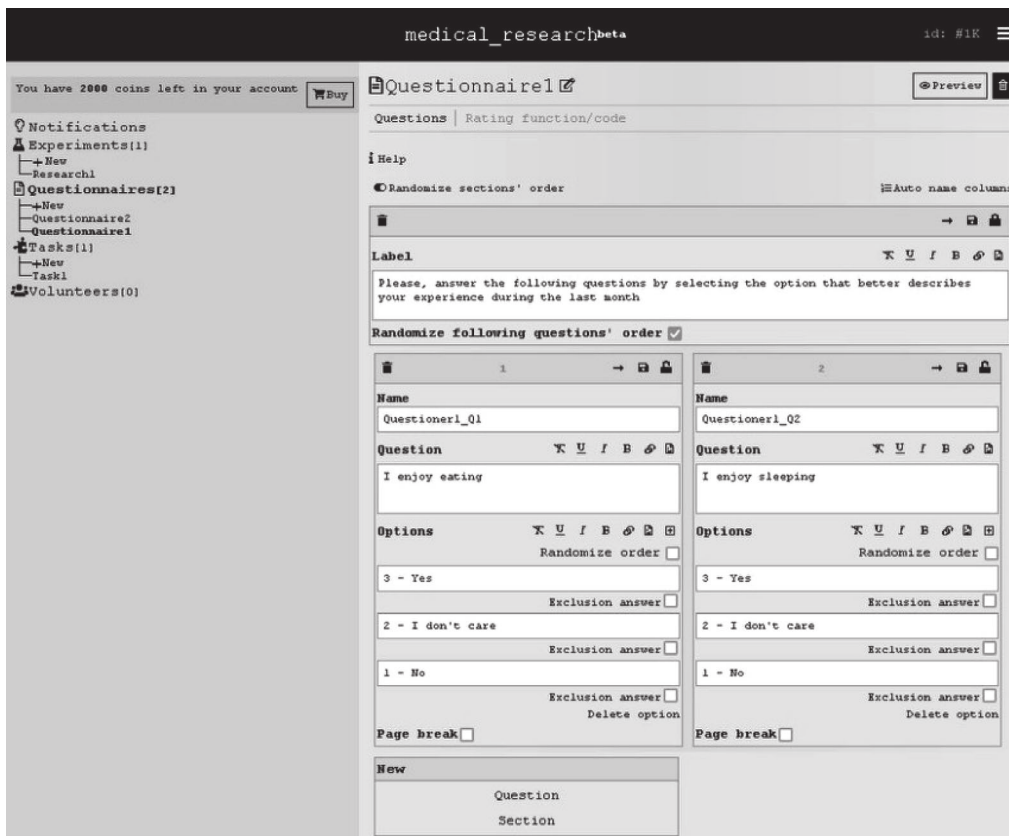

Figure 1. The researcher's personal repository can be seen on the left. The repository contains all the tasks and questionnaires that the researcher has created on the platform. On the right, the process of creating a new questionnaire is displayed.

is also the option to provide the scoring algorithm that would automatically rate the questionnaires. The algorithm should be coded using JavaScript programming language and takes into account the answers that are given to each question, but can also include the actual time when each questionnaire was completed and the response time for each question. In the algorithm, the researcher can determine the way the scored components of the questionnaire will be presented during the overview of the results of each participant but also the way that the results will appear in the final database.

As for the task, it can either be executed locally using the platform's resources or through an external link. In the first case, where the task is locally executed, the researcher is asked to upload the task's code. If the task is to be executed through other means, the researcher needs to provide the uniform resource locator (URL) where the volunteers will be redirected. In both cases, the platform offers the option for the task data to be stored on the platform's side. As with the questionnaires, if the task is accompanied by a scoring algorithm, this could also be defined.

Once the questionnaires and the task are ready, the researcher then needs to define the experimental design. In our scenario, our experimental design comprises of two stages, as the questionnaires and the task would be administered at baseline and 7 days afterwards. For that, the researcher would input all the elements of the experiment twice, and in the order that they would like them to appear. The researcher would then group them per stage by adding a prefix of their choosing, for example "t0" for those of the first stage and "t1" for the second stage of the experiment. The prefixes are also useful for distinguishing the results from the tasks and questionnaires that come from the different experiment stages as well as all the other variables that are created as outcomes (e.x. scoring results) and are included in the final database. As in this experiment the questionnaires would appear in a randomized order and the task would always be administered last in line, the researcher would have to select the appropriate randomization option but also "lock" the position of the task, so that it would always appear in the end. Since the two stages of the experiment are one week apart, the researcher should define the duration of the pause after the

Figure 2. Once the questionnaires and task are finalized, the researcher can start organizing them to match the experimental design. For our example experiment, the questionnaires and the task would be administered at baseline and 7 days afterwards. To do this, the questionnaires and the task are inputted twice, as shown on the right-hand side of the figure. The tasks are grouped per stage and the researcher has chosen the prefix "t0" to mark the questionnaires, task and the experiment variables that will be created for the first stage of the experiment. As the two stages of the experiment are 7 days apart, the pause duration has been set to 10,080 mins.

completion of the task of the first stage accordingly (fig. 2).

The researcher can also define which demographic data their volunteers need to consent to be shared. Finally, before the experiment is ready to run the researcher needs to specify which information about the experiment the volunteers would need to know prior to participation. This information usually includes the description and purpose of the experiment and the experimental design along with all the necessary information around the ethics approval for this experiment and the volunteer's consent. At this point, it is worth mentioning that the design of the experiment is not necessarily executed by only one researcher. The platform offers the researcher the option to invite other colleagues and form a team. It is also possible to define which parts of the experimental procedure are accessible and amendable by each member of the team, depending on every researcher's role and responsibilities. Once the experimental procedure is set up and the team of researchers in place, it is time to recruit volunteers and collect and manage the data.

2.4. Volunteer recruitment

The platform offers three options concerning volunteer recruitment. These options could be used simultaneously by the researcher to recruit volunteers for each experiment. These are: (a) The experiment to be visible and accessible to all volunteers who have subscribed to the platform, (b) through a link that can be used to make the experiment accessible, for example to other recruitment platforms or social media, and (c) through special links that represent personal invitations, which could be sent to participants via email. The first two options, by design, preserve the volunteer's anonymity as this can only be revealed if they wish to do so. When the third option is used, the anonymity of the volunteers cannot be preserved, as the researchers would send the invitation link directly and personally to each volunteer they wish to recruit.

Let us assume that for the example experiment we describe here, we already have selected the group of volunteers we aim to recruit as a patient group but not the control group. This is often the case in medical research, especially in psychology and psychiatry. In that case, either the researchers themselves or members of the research team could send personal invitation links to the volunteers that constitute the patient group. To mark this group as the patient group, the researcher has the option to create a variable that also represents a new column in the final database or a keyword for the participant of each experiment to which the researcher would assign a specific value, for example "1" for the patient group. That way, the groups of volunteers that will take part in our experiment could also be distinguished. As the volunteers who would constitute the control group are not predetermined, through the platform, the experiment could be shared with volunteers who wish to take part in research.

2.5. Data collection

Once the experiment is set up and the volunteer recruitment process is in place, data collection can begin. During data collection the researcher or the research team can inspect the answers that are submitted by the volunteers in real time. The database, including the experiment's data, is immediately updated and can be downloaded and stored locally, for further analysis. The database elements that are available for downloading include the demographic information, the raw answers, the rated answers, the completion time of each questionnaire and task, the keywords and extra columns that the researchers might have created (fig. 3). Throughout the process of data collection, the researcher can communicate with the volunteers, and if necessary, change the experimental procedure by adding, removing, or changing the order of the tasks and questionnaires even at the volunteer level. The platform offers researchers total control of the experimental process.

2.6. Volunteers

After logging into the platform, volunteers can fill in, access or amend their demographic information, view notifications, overview the experiments that they participate or search for new ones.

The demographic information that volunteers provide, not only serves certain experimental purposes, but also could be used as a filter that would allow them to only view experiments that they fulfil the participation criteria for. The demographic information of the volunteers is protected and not shared with the researchers unless the volunteers consent to revealing such information. If a researcher wishes to obtain such information from the volunteers, they need to specify which information they need to know and obtain the consent of the volunteer before these data are shared.

The platform notifies its users of any important changes to the experiment they are participating in. These changes include invitation messages, changes in the consent form, and updates on the experimental procedure. Specifically about consent, the volunteers are notified for any changes in the consent form of the experiments they take part into, as they need to reaffirm their approval to continue with
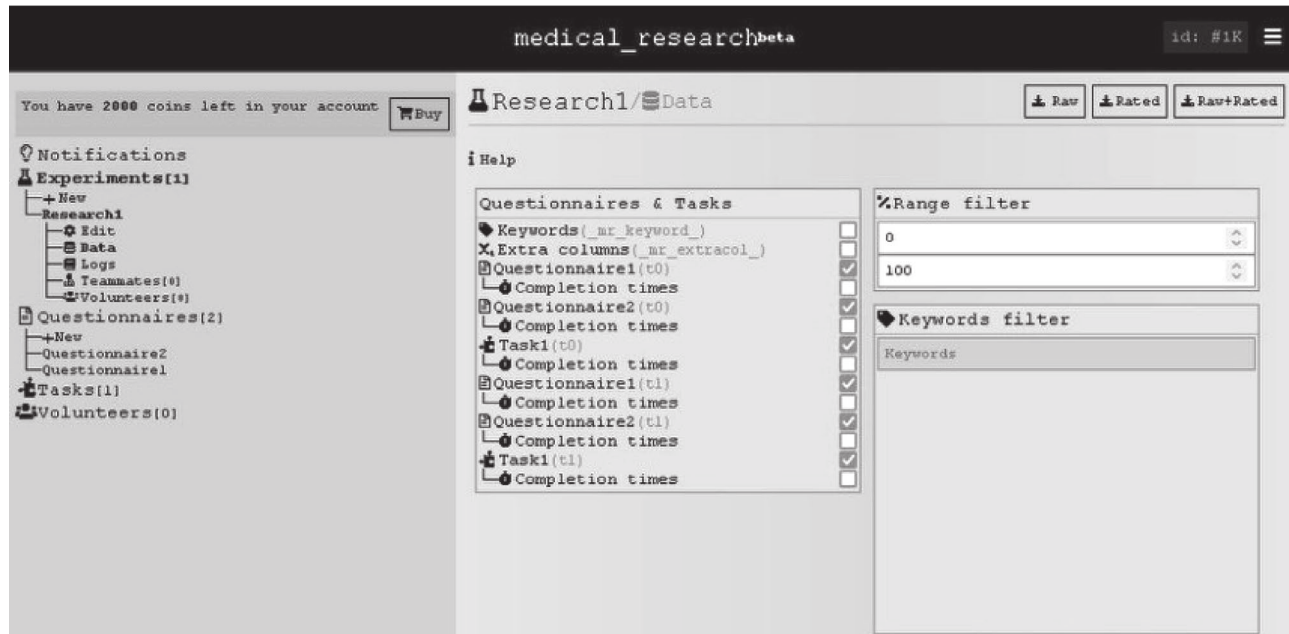
Figure 3. Researchers can select the variables that will be included in the database. In our example experiment, the completion times that come from the first stage of the experiment are marked with "t0", while those that are produced during the second stage of the experiment are marked with "t1". The database, including the experiment's data, is immediately updated and can be downloaded and stored locally for further analysis. The researchers can select, by ticking, which elements and variables of the experiment will be downloaded. The option to download the raw data, the rated data or both is available on the upper right corner of the screen.

the experiment. Notifications can also be mailed to the participants' personal email address.

Our platform tries to preserve the anonymity of the volunteers and to achieve this, from the researcher's point of view, each volunteer is represented by an alphanumeric string. For every different researcher, the same volunteer will be represented with different such strings. The volunteers anonymity cannot be preserved, as explained before, when the volunteers choose to reveal their identity themselves through direct messaging with the researcher or by answering to experiment questions. Additionally, the identity of the volunteer must be considered known when they accept personal messages from researchers.

In our research example, the volunteers who constitute the patient group will receive personalized invitations to participate in the experiment. Volunteers of the control group will find the experiment through the search function of the platform. Once a volunteer declares that they wish to participate in our example experiment, they need to accept the consent and then complete the questionnaires and task of the first experimental stage. Volunteers can pause and resume the experimental process as many times as they wish to. Once they have completed the first stage of data collection, they will be notified 7 days later about the completion of the second stage.

All volunteers can terminate their subscription to the platform at any point throughout the experimental process.

2.7. Proof of applicability

The platform has been used to run actual experiments. It has served as a data collection tool used by different research teams and several scientific articles have been published from these experiments.[3–7] This demonstrates that our platform can handle a large number of volunteers and the user experience that it offers does not prohibit its use by many different clinical populations; for example autistic or attention deficit hyperactivity disorder (ADHD) individuals.

3. DISCUSSION

This article is an introduction to a new tool that we believe could greatly improve the experimental processes, especially in medicine, by making it more efficient for both researchers and volunteers. Our platform allows researchers to set up their experiment, invite and recruit volunteers and collect data remotely. Additionally, it gives the researcher complete control of the experimental process as well as the management of data collection, the output of the results and the creation of a final database which could be used for further analysis.

The concept for this platform was conceived when the need of such a tool arose during the data collection process for the PhD thesis of the author. Standard practices for data collection in medical research, at least in Greece, include the in-person administration of questionnaires and tasks. Those tasks and questionnaires are usually rated by the researchers and then inputted manually in an electronic database. This is a time and energy consuming process that has disadvantages for both parties, the researchers, as well as the participants, and if not done properly, it could also compromise the quality of the research data.

The main problem that could arise from this way of data collection concerns the researcher bias. When data are collected in person and the different questionnaires are administered to volunteers by the same or different researchers, it is common that the researcher could implicitly influence the volunteer. That could lead to detecting trends in the data that are the result of researcher bias.[8] Additionally, when multiple researchers are involved in the data collection process and interact with the volunteers, the quality of the collected data could significantly differ between researchers and thus further compromise the outcome of the research. When transcription of the questionnaires is required, this process could also be subject to errors. Finally, an in-person data collection does not by any means guarantee that there will be no missing data. In this case, when answers to tasks and questionnaires are missing, another in-person session with the volunteer is required. This is potentially difficult to arrange and time and often money consuming, thus it almost never occurs.

The platform does not by any means aim to substitute the relationship between a medical professional or experimenter with their patients and volunteers. It offers, however, a tool that could be used to help improve the quality of data collection by bypassing some of the problems of in-person data collection and making it more efficient, accurate and flexible, for both sides. It has been designed and developed in such a way that can easily be used with average computer knowledge. Those who are more proficient with computers and coding can profit more from the platform's capabilities.

The platform aims to promote spontaneous participation to research that is not guided by financial motives, as that oftentimes could compromise the quality of the collected data.[9–11] Finally, it is important to mention that the primary language in our platform is Greek, which makes it even more unique and user-friendly to Greek researchers and volunteers.

4. LIMITATIONS

Although our platform has many characteristics that set it apart, compared to the other online tools that have been developed for data collection and analysis, it also has certain limitations. Firstly, unlike other online platforms that are mainly used for volunteer recruitment, our platform does not offer the option for the volunteers to be paid for their research participation directly through the platform. As a result, we do not expect that many volunteers would be keen to subscribe and participate in the research. In that respect, the platform mostly relies on researchers in order to attract volunteers for experiments. Additionally, there are certain types of data that their collection is not yet natively supported by the platform (researchers can develop tasks for that purpose), for example voice recordings, and this might limit its use as these types of data might be a requirement for certain experiments. The majority of the platform features are easy to use by most people, as they do not require specific knowledge of computers or programming. Certain types of functions, however, that the platform offers, including the automatic marking of tasks and questionnaires, require composing and/or amending coding algorithms which require advanced programming knowledge.

Remote data collection has many advantages for both the researchers and the volunteers, but the inevitable absence of the researcher from the physical place where the data are collected requires careful planning of the research to ensure maximum quality of the collected data. As a result, when researchers design their experiments, they need to take into account the fact that they would not be able to entirely control the environment during data collection as that would differ for each volunteer. Thus, experiments that are very limited by or sensitive to the environmental conditions might need careful planning in order to be executed on the platform. Finally, our platform provides the means for data collection but it cannot control or guarantee the reliability of that process or the fact that appropriate research practices are followed. This is a responsibility that entirely burdens the researchers and their teams.

5. CONCLUSIONS

Despite limitations, we believe that this platform could become a valuable tool that would greatly assist in experiments and data collection, especially in the psychiatric and psychological research. That would make experimental process readily accessible to volunteers, as well as easier and tailored to the researcher's needs with the ultimate goal to promote scientific research.

ΠΕΡΙΛΗΨΗ

medicalresearch.gr
Εισαγωγή σε μια διαδικτυακή εφαρμογή για τη συλλογή ερευνητικών δεδομένων

Β. ΜΑΝΤΑΣ

Α' Ψυχιατρική Κλινική, Εθνικό και Καποδιστριακό Πανεπιστήμιο Αθηνών, «Αιγινήτειο» Νοσοκομείο, Αθήνα

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Η σύγχρονη τεχνολογική εξέλιξη προσφέρει τη δυνατότητα ανάπτυξης εφαρμογών προς διευκόλυνση και προώθηση της ιατρικής έρευνας, χωρίς ωστόσο να υποβαθμίζεται η σημαντικότητα της σχέσης ανάμεσα στον ιατρό/ερευνητή και τον ασθενή/συμμετέχοντα. Το medicalresearch.gr αποτελεί μια διαδικτυακή εφαρμογή, η οποία εξυπηρετεί την απομακρυσμένη συλλογή δεδομένων. Παρέχει στους ερευνητές τη δυνατότητα σχεδιασμού του πειράματός τους, διαχείρισης των συμμετοχών σε αυτό, χορήγησης ερωτηματολογίων και δοκιμασιών τα οποία βαθμολογούνται αυτόματα, ενώ οργανώνει όλα τα συλλεχθέντα δεδομένα σε μια ηλεκτρονική βάση έτοιμη προς επεξεργασία και ανάλυση. Βάσει των διαθέσιμων λειτουργιών και χαρακτηριστικών της εφαρμογής, αλλά και των μειονεκτημάτων που διέπουν τη μη αυτοματοποιημένη εκ του σύνεγγυς συλλογή δεδομένων, θεωρούμε ότι η εν λόγω εφαρμογή μπορεί να αποτελέσει ένα χρήσιμο εργαλείο στη διευκόλυνση της ερευνητικής διαδικασίας και στη βελτίωση της ποιότητάς της.

Λέξεις ευρετηρίου: Διαδικτυακή εφαρμογή, Ερευνητικό εργαλείο, Συλλογή δεδομένων

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Corresponding author:

V. Mantas, First Department of Psychiatry, National and Kapodistrian University of Athens, "Eginition" Hospital, 72–74 Vassilisis Sophias Ave., 115 28 Athens, Greece
e-mail: mantas.vasilios@yahoo.com