



BMP Final report

Introduction

Dystonia Europe launched the MyDystonia app in 2015 with the aim of helping adult patients with dystonia record different aspects of their quality of life living with dystonia. The app helps the patients to keep track of their daily well being and state of mind, which is stored in a secure database and is used to plot several types of charts which can be used during the periodic meeting with their physician. These periodic meeting often have severe time constraints and patients are being asked about how they have been since the last meeting or therapy session. For humans it's nearly impossible to remember all significant events of a period that can easily cover six months, and often even longer. This is where MyDystonia can help. By using the electronic diary of MyDystonia on a regular basis, all events have been recorded and can easily be made visible on charts to be shared with their physician. This saves a lot of precious time during the meeting and much more details are available for both the physician as the patient. This information helps in optimizing treatment with the aim of increasing the overall quality of life.

With the help of many different national patient organisations we were able to translate MyDystonia in 10 different European languages and we have been able to set up an extensive ambassador program. Our ambassadors help us to promote MyDystonia among patients and physicians and help us by providing support to users of MyDystonia on a national level, often in the user's native tongue.

Based on our experience with launching, supporting and maintaining the MyDystonia app we want to set up a new platform, covering not only the current adult dystonia patients, but also children with dystonia. While writing this document we have met with other European patient. Other neurological patient organizations have shown great interest in using this new platform. At the same time we want to provide a whole new means of acquiring and providing information for researchers/ research projects in the area of neurological brain diseases. Our working title is MyBrainNet .

About the MyBrainNet platform

The past year Dystonia Europe has talked to many patients, national patient organisations, physicians and researchers about the potential of the next generation of MyDystonia. Although MyDystonia have seen many positive reaction, we also got a lot of suggestions to make MyDystonia much more useful to other groups, such as researchers. At the same time we have been in contact with other neurological brain related European patient groups, such as Restless legs. All this information resulted in the creation of a plan to create a new platform, suitable for multiple user groups, such as adults with dystonia, children with dystonia, adults with restless legs syndrome and even more. The new platform will also capture information which can be used by multiple research projects well into the future.

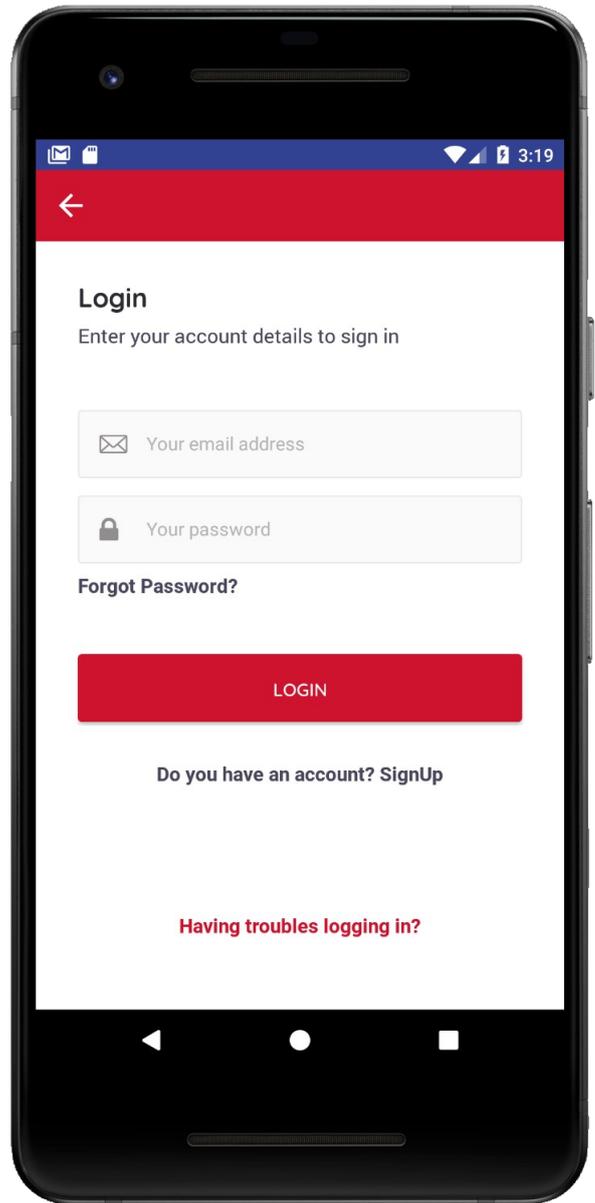
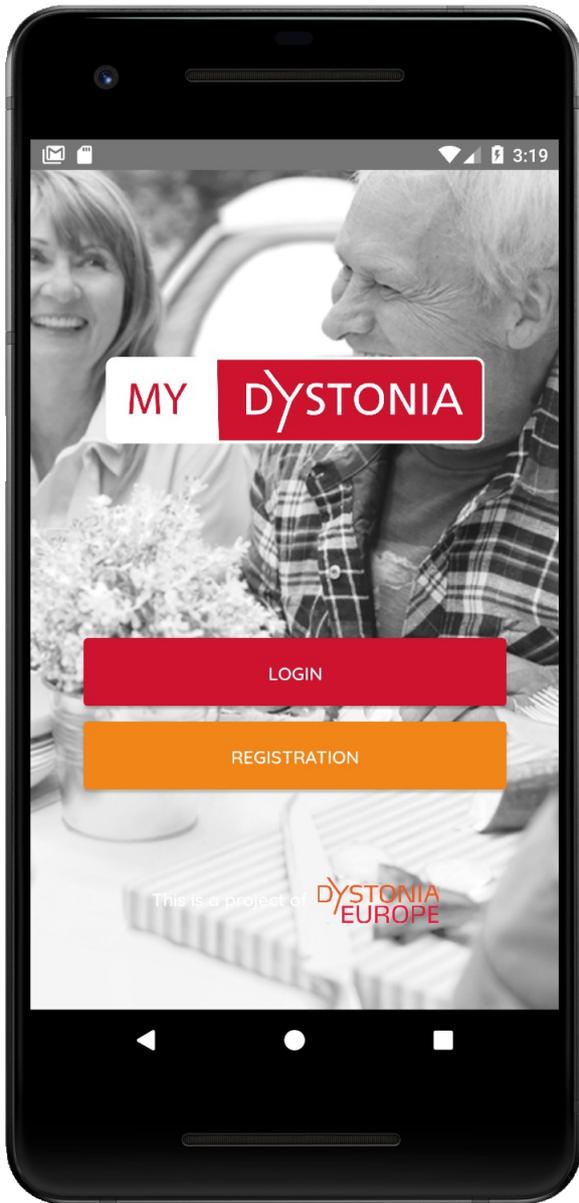
Creating the MyBrainNet platform

With the aid of BMP grant, and several other supporters, we were able to develop this project. At this moment we're finalizing the content of the MyDystonia app, the first app to be connected to the MyBrainNet platform.

Because the MyBrainNet platform is mostly abstract and has no visual representation other than the website, the following pages will describe the MyDystonia app, were the current functionality of the platform is shown.

Splash screen and login form

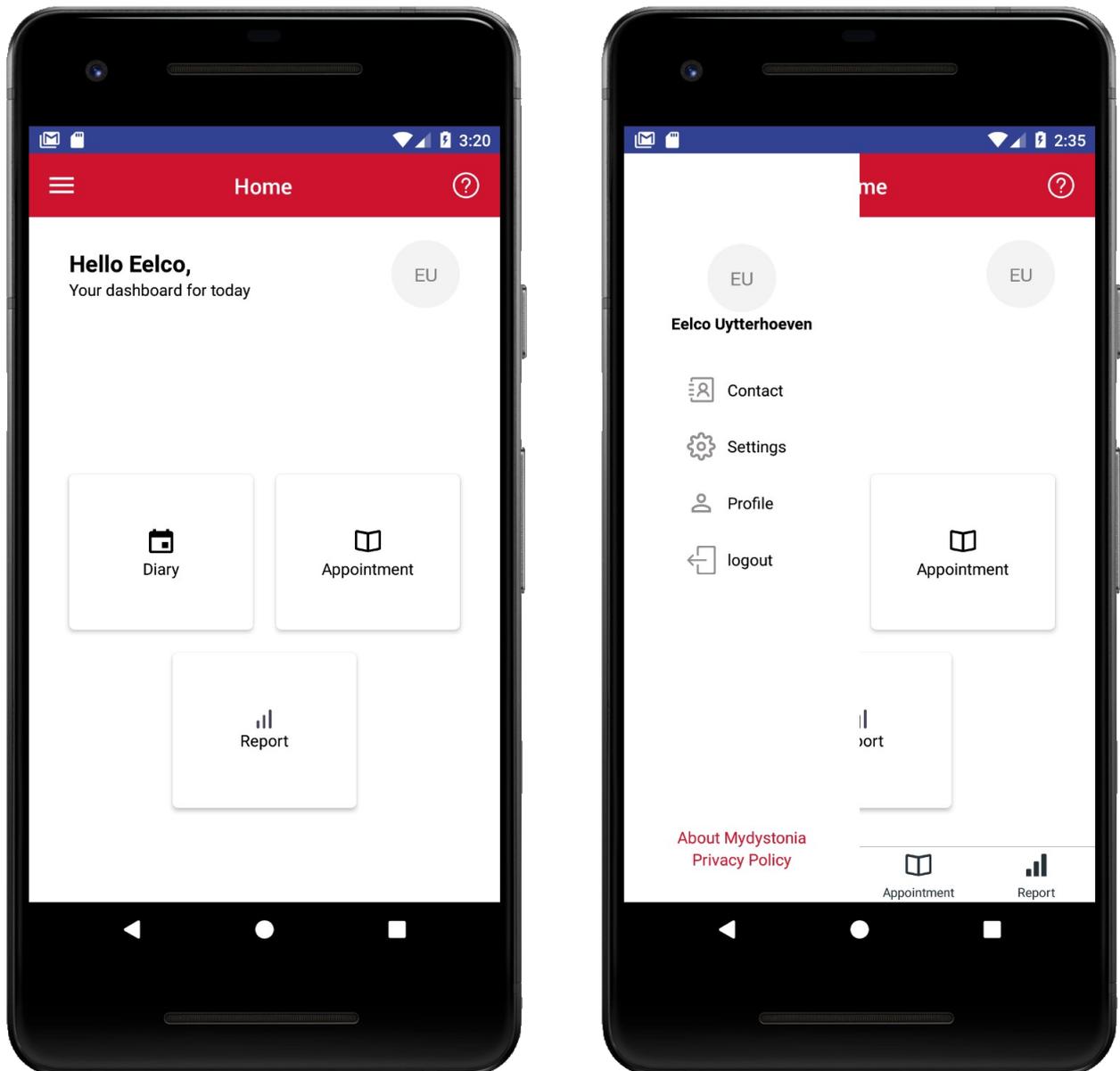
These images show the splash and login screen, when someone opens the app. An existing user will access the app with their username and password, while new users can register themselves. Users who have forgotten their login details, can enter a 'password forgotten' process.



Dashboard and menu

After logging in the user will be led to the dashboard, where all main functions are being displayed. For this first phase we concentrated on creating the digital diary. In the future any new modules with new functionality can be added here.

The menu shows the secondary functions of the app, as logging out and updating the user's profile.

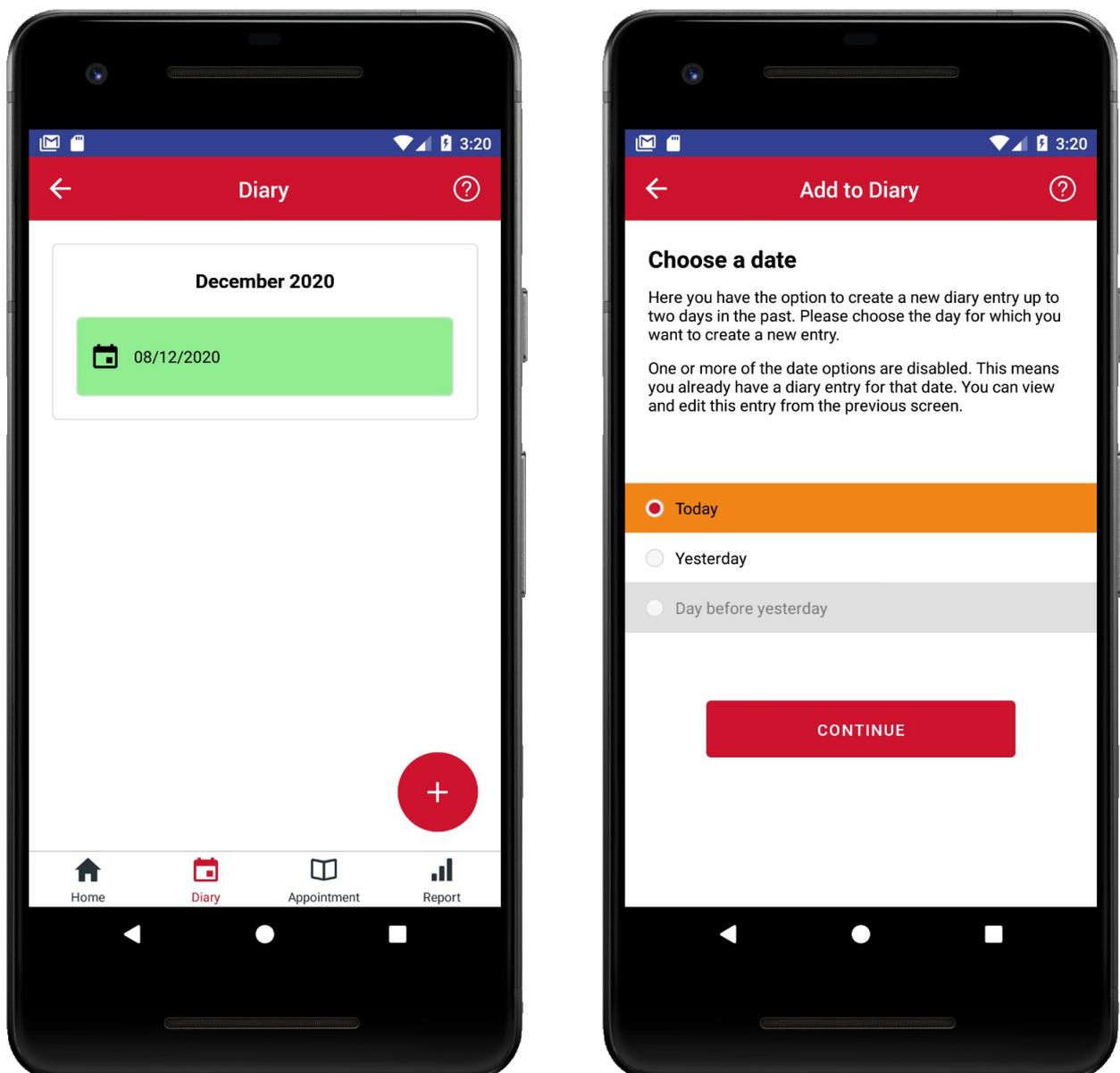


Diary listing and creating a new diary entry

When a user clicks on the diary-button on the dashboard, a screen will display all previously made entries, together with a button to create a new entry.

A user can always open previously made entries and see that information. Diary entries of less than 3 days old can also be edited, allowing user to improve their entries or add additional information.

When a user clicks on the plus-button, the user can create a diary entry for up to 2 days in the past. This allows users to create diary entries about important thing that happened some days ago, if they weren't able to add this to the diary at that moment. MyDystonia allows entries for up to 2 days old.



Questions and question types

The diary will display a series of questions. A user is requested to answer these questions. The questions have been created in collaboration with a group of medical specialists, specifically for the MyDystonia app. The questions, and answers, should create a good overview of the patient's well being in the last few months.

The medical advisors have a choice of using several 'question types'. The type determines the way a question is presented in the app and the options a user has in answering. The question types have some configurable settings, which will be mentioned first. After that there will be a listing and description of the question types.

Configuration

Every question can be configured to be 'skippable', meaning that a user doesn't need to answer the question and can move on to the next one.

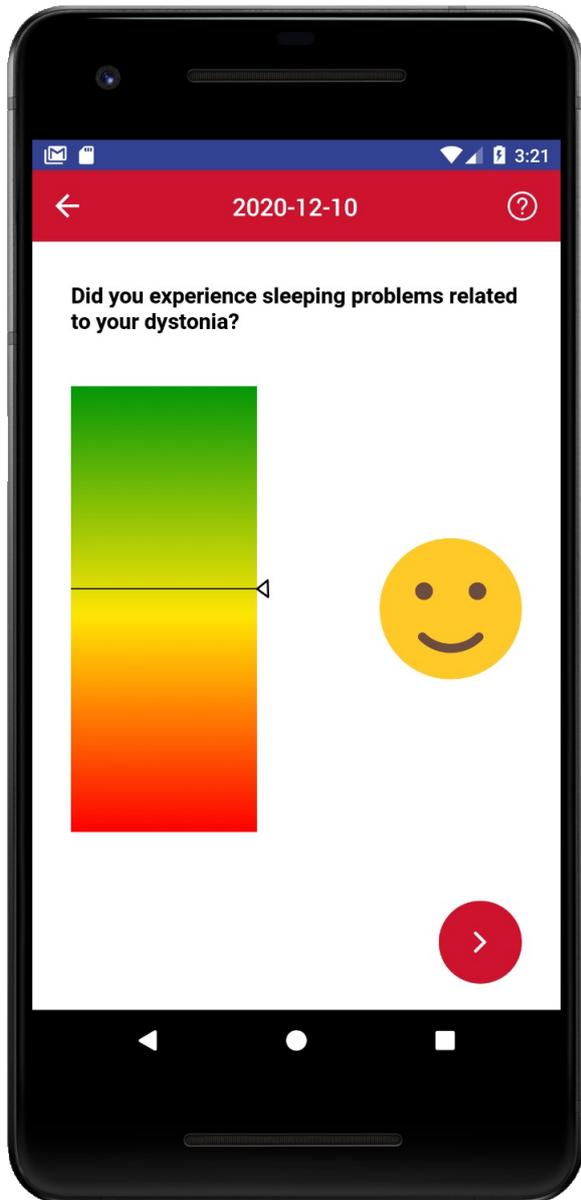
All questions have the option to be connected to one or several types of dystonia, and one or several types of treatment. When a user registers or edits it's profile, the user has the option to select one or more types of dystonia (s)he may suffer from. And also select one or more treatments that (s)he has had. This information allows us to serve specific questions to specific people with type of dystonia and/or treatment.

Most questions can be configured to be 'user manageable', meaning that a user can add new answers. As an example; a question about sport will list several common sports to choose from. But a user can be allowed to add new sports to the list of possible answers.

Most questions can be configured to allow one or multiple answers.

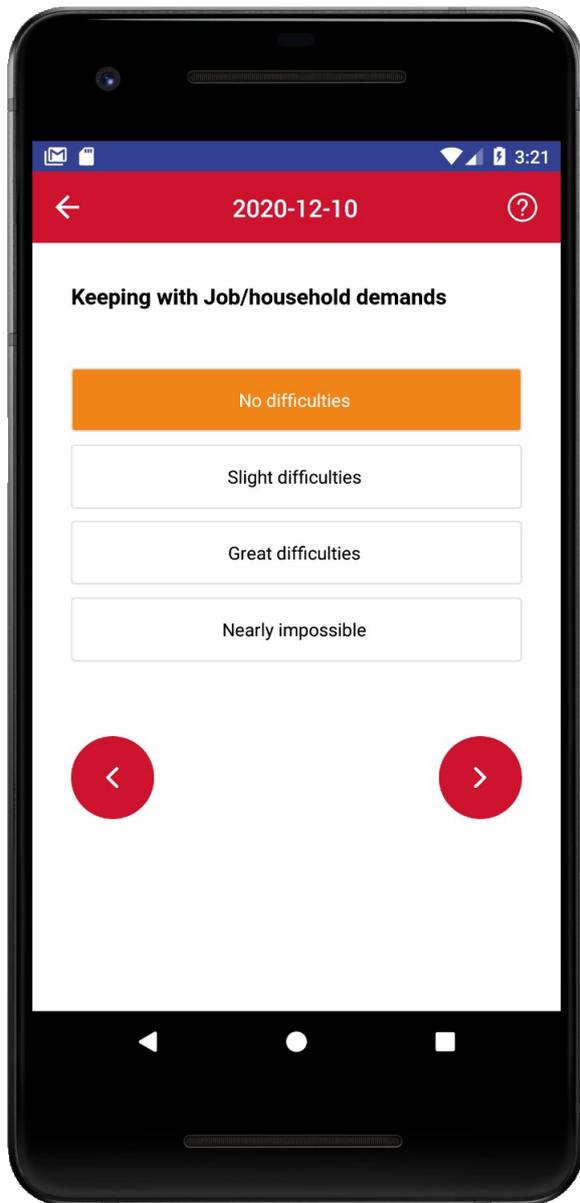
Question type: Scale

A scale question can be used for questions when we need to know something based on a (rating) scale. A question about a user's night sleep is well suited for this. The scale question is configurable to set a minimum and maximum value and will record a numeric value accordingly. Additional feedback is given to the user by displaying an appropriate smiley face icon.



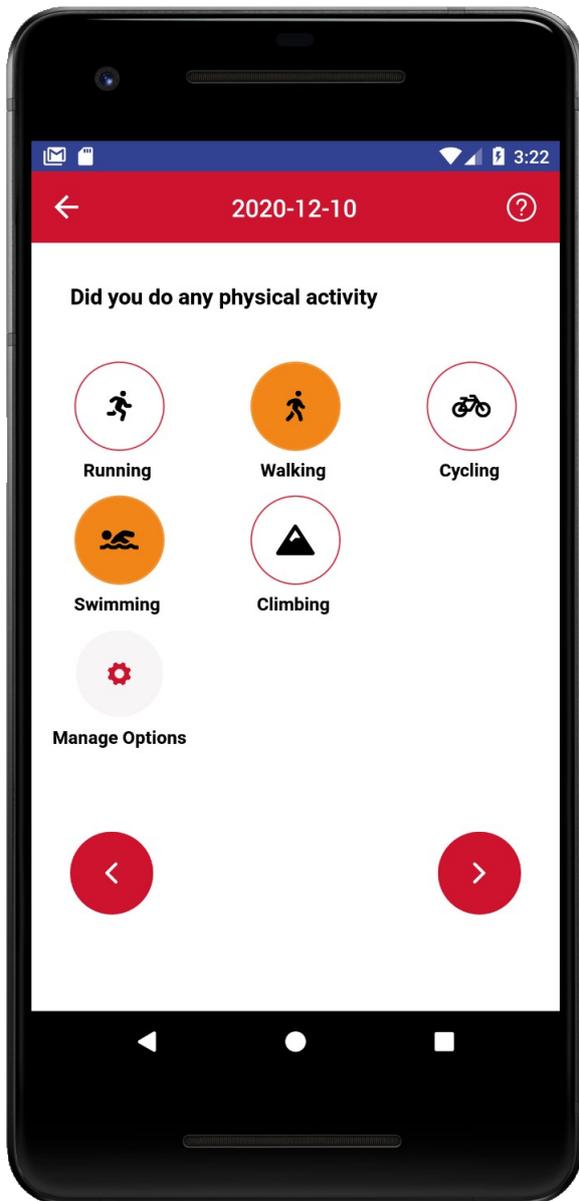
Question type: text

A text question will display a series of answer-options as text. A user can click on any of these options. This question type can be set to allow multiple answers.



Question type: icon

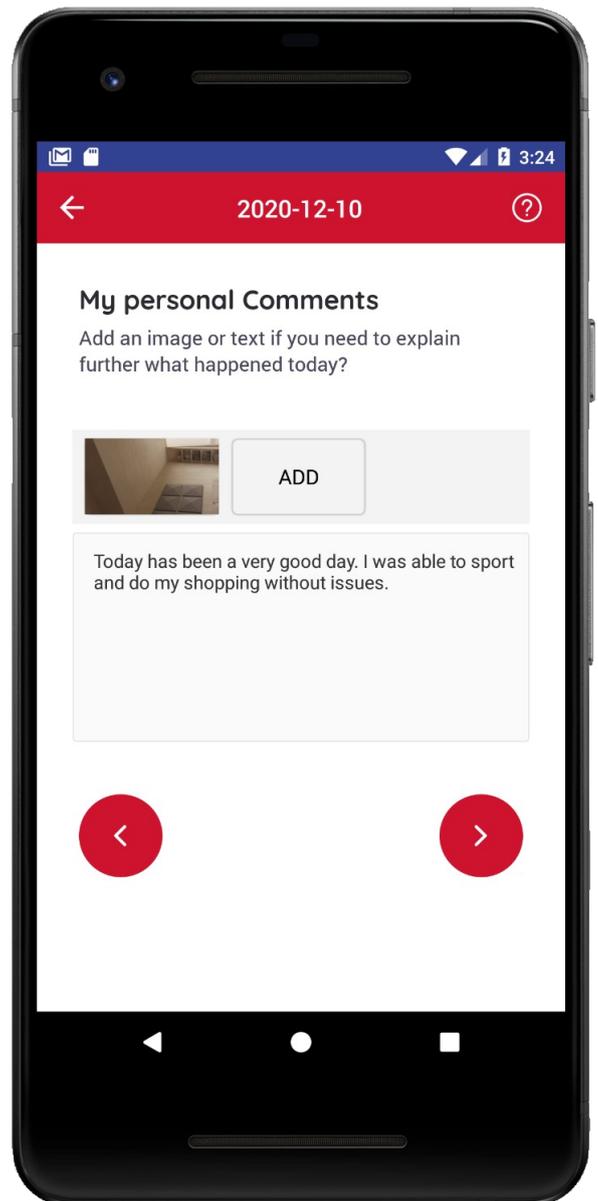
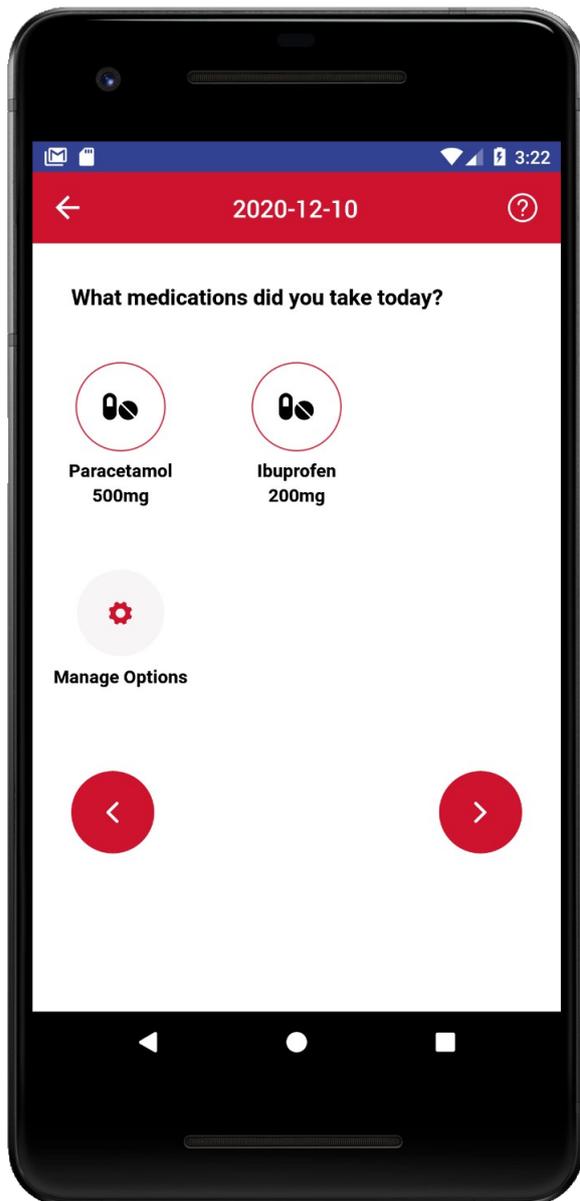
For some questions it's more practical, or more pleasing, to use icons together with some text. This can be achieved with the icon-type and is most suited for use short texts and distinct icons. This question can be set to 'user manageable' and to allow multiple selections.



Medication en additional information

After the series of questions have been presented, the user will be shown a screen where the user can record any household medication (s)he may have taken. This information can be useful in the communication with their medical specialist.

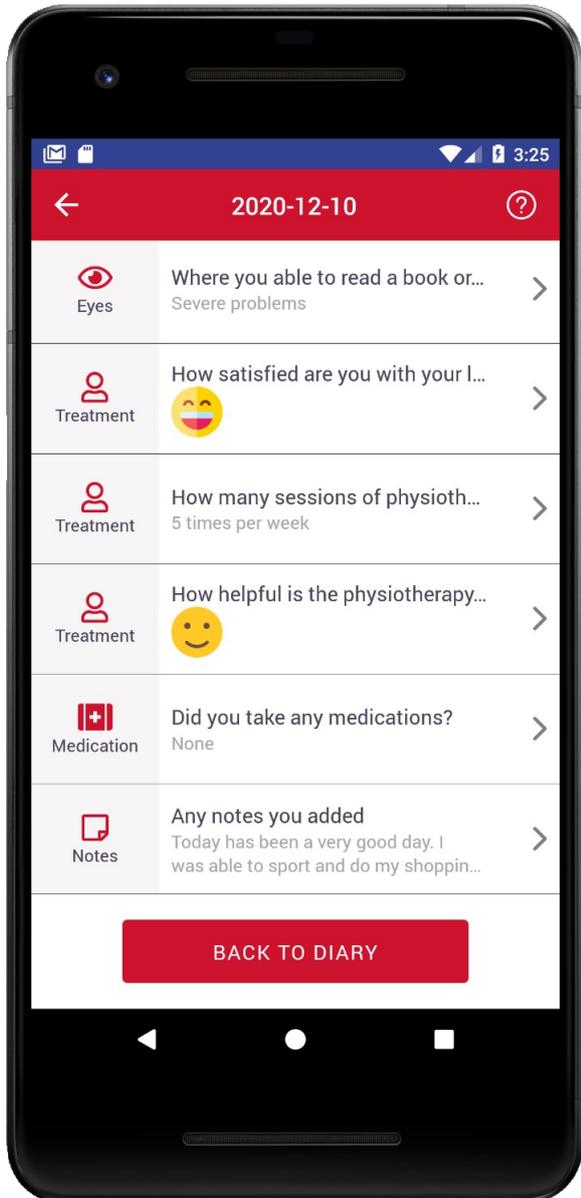
After the medication screen the user can add some additional information to the diary entry. This can be text, but also one of more images. This information will be shown in the app's report.



Diary event overview

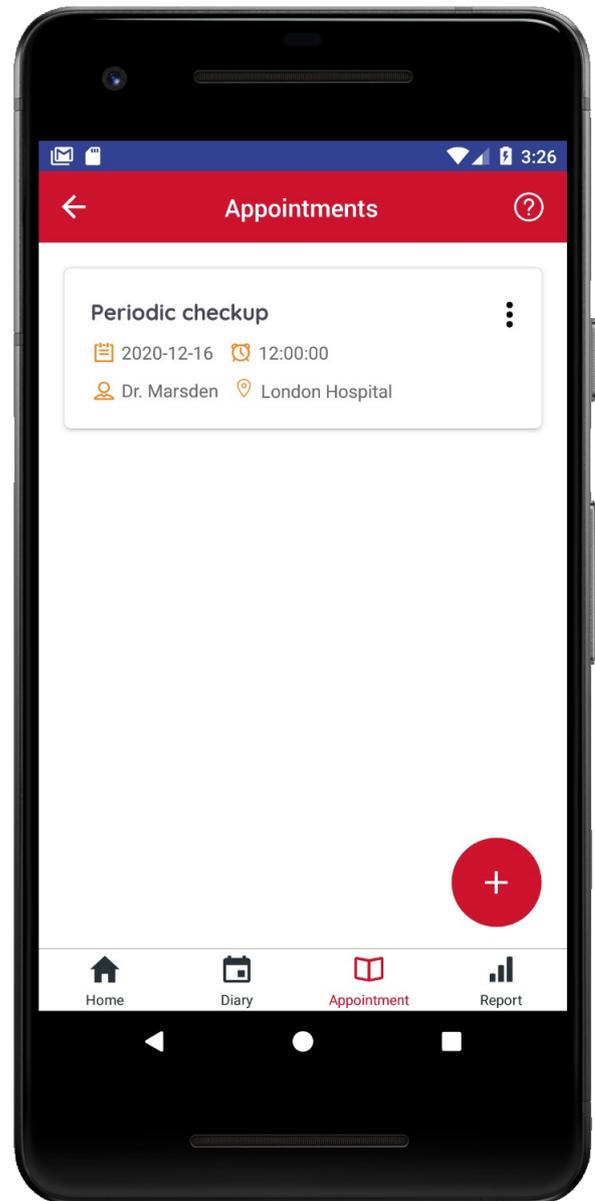
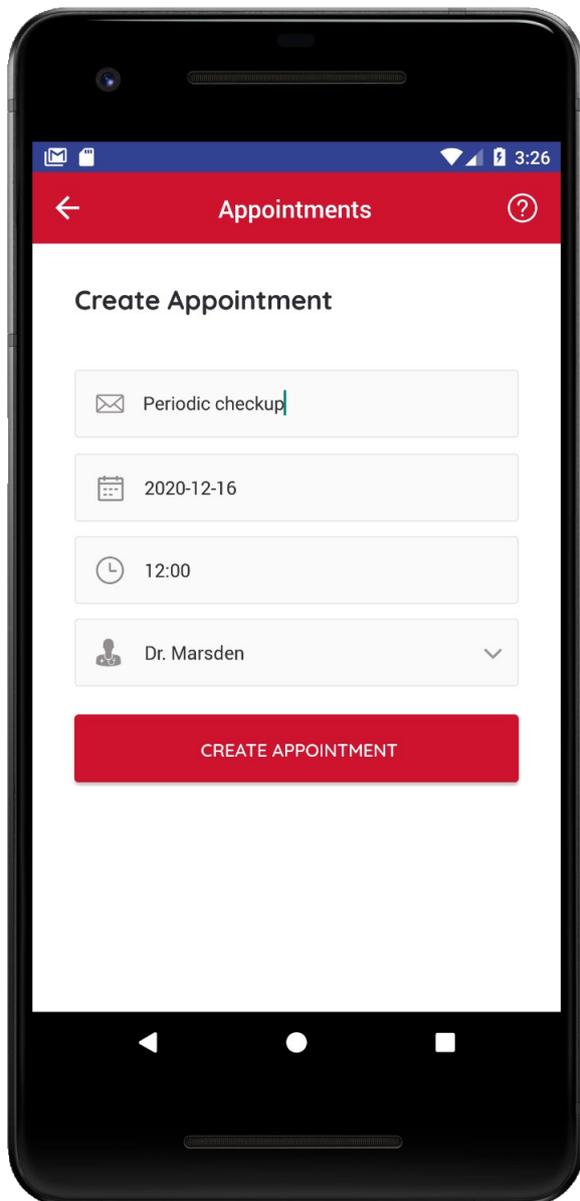
After the process of answering questions, medication and adding additional information, everything is presented on the overview page. This page gives a quick overview of all questions and answers, and also gives the user the option to alter any of these answers.

When a user is satisfied with the result, the user goes back to the dashboard screen.



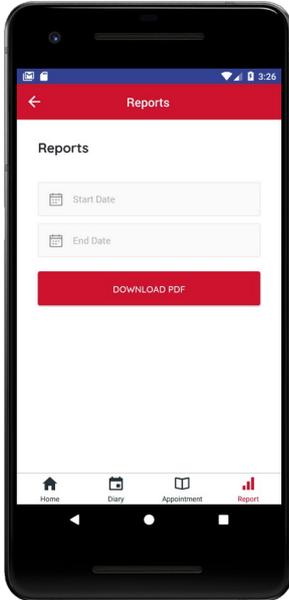
Appointments

To add some additional functionality to the MyDystonia app and MyBrainNet platform, a user has the ability to add their (medical) appointments. This module has been created both to add some extra functionality, but also as a show- and test case for adding additional modules to the MyBrainNet platform.



Reports

A user can create a PDF report for any given period. The report will create a PDF with one day per page and on the final page, several line charts for any scale-question. This will give a compact overview of the requested period and can easily be shared with, for instance, their medical specialist.



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22 July 2020

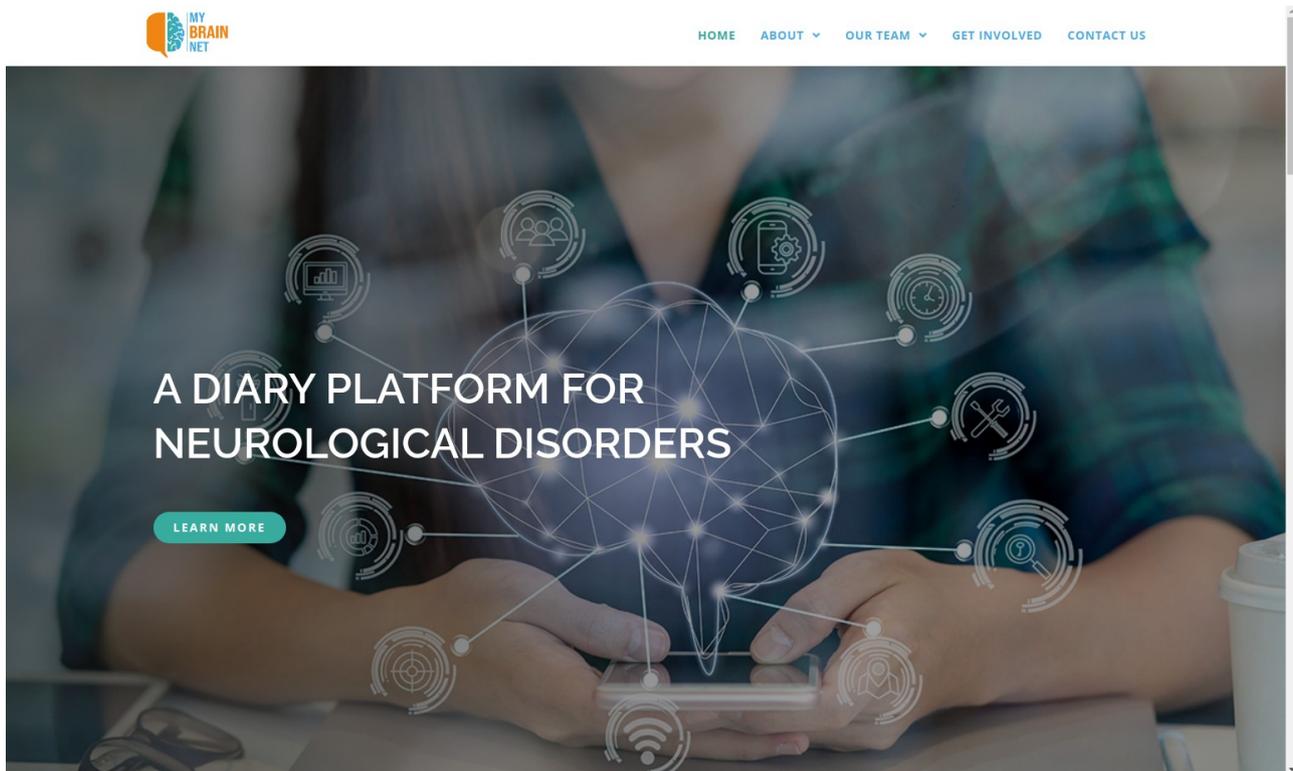
Involuntary movements	Not at all
Overactive muscles	Not at all
Abnormal posture	Not at all
Did you experience sleeping problems related to your dystonia?	<div><div style="width: 40%; background-color: #00ff00;"></div><div style="width: 60%; background-color: #808080;"></div></div> 4 / 10

<u>Medication</u>		<u>Personal notes</u>
Paracetamol	2000 mg	This is some note text... And some more

Website

In December 2020 we've launched the MyBrainNet website. On this website we give some comprehensive information and give interested parties the ability to connect. All new apps that will be connected to the MyBrainNet platform will be listed here for promotion and easy accessibility.

The website can be visited at: <https://mybrainnet.eu>



Final launch of MyDystonia

While the MyBrainNet platform is fully operational, the creation of good quality questions has taken much more time than anticipated. The duties and workload of our medical advisors have been under great stress this year with all the Covid related measures, resulting in less time available for MyDystonia. We expect to finalize the questions this month, so we can publish the new MyDystonia in January 2021.

Communication about the project

Information about the project has been shared on the various Dystonia Europe communication channels (newsletters, newsblog on website, social media channels) and at meetings such as Dystonia Europe Members' Meetings, and annual Think-Tank Meetings with partners and MyDystonia Ambassadors' Meetings. See links below.

MyBrainNet in newsletter:

<https://dystonia-europe.org/2018/12/mybrainnet-a-digital-platform-for-brain-diseases/>

<https://dystonia-europe.org/2019/12/mybrainnet/>

MyDystonia in newsletters:

<https://dystonia-europe.org/2019/11/my-dystonia-2-0/>

MyDystonia Ambassadors meeting in Dublin 2018 :

<https://dystonia-europe.org/2018/10/mydystonia-ambassador-meeting-dublin-2018/>

MyDystonia Ambassadors meeting in Newcastle 2019:

<https://dystonia-europe.org/2019/11/4th-mydystonia-ambassadors-meeting/>

Participation at EFNA Workshop

In autumn of 2018 EFNA organised a workshop for young patients' advocates. Dystonia Europe was invited to present the MyBrainNet project. Then followed an interactive session for the participants to give feedback and comments on the project.

<https://www.efna.net/report-patient-advocacy-in-the-digital-world-efnas-young-peoples-workshop/>

Next steps

Dystonia Europe plans to continue to inform about the MyBrainNet platform and its possibilities to EFNA member associations as well as other patient organisations and stakeholders. For anybody who is interested the MyBrainNet website contains all information on the project and how to join.

We hope to see that the platform opportunities will be used by others in order to benefit the greater neurological patient community.