# MyPathway

Telemedicine in MND (TiM) is a mobile health app for your phone, tablet or computer. It aims to improve communication between you and the National MND service (Ireland). It is hosted on a platform called MyPathway, an app that was developed by MyPathway Solutions Ltd, a VitalHub UK Company.

# This app:

- Encrypts and stores data inputted by you on your phone or tablet (once you install the app)
- Stores no information on your device after you log-out if you use a browser to access the app
- Captures technical information about the device you are using, and how you use the app – this data is only used to improve the app
- Shares the information you enter with healthcare professionals responsible for your care and with computer system administrators to enable them to fix technical issues

# For Patients, this app:

- shows the Patient, information about their condition and treatment, based on information provided within the app
- will ask the Patient, to complete questionnaires about their health, their opinion about the self-management advice they receive, whether the advice has helped, and their overall experience of our care

# For Carers, this app:

- shows the Carer, information provided within the app
- will periodically ask the Carer, to complete questionnaires about their wellbeing and experiences of caring
- will link the information Carers give to the Patient within the system to ensure the care team can interpret all the information correctly

# Body

## The Application

The National MND Service in Ireland in Beaumont Hospital in partnership with Trinity College Dublin are offering you Telemedicine in MND (TiM) hosted by the MyPathway app to allow us to monitor your condition, provide you with care and monitor the care we provide to you, or the person you care for.

# What information does the app use?

# Information you enter

If you are a Patient, the app uses secure forms to collect your full name, date of birth, email address and mobile phone number details. If you are the Patient's Carer, it uses secure forms to get your name and contact details, and Your date of birth for identification purposes, as well as to identify the Patient for whom you are caring.

The app also asks you for your email address and/or mobile phone number as part of the sign-up process – this is so it can create your personal account, confirm that it is you creating the account, link it to your records at your MND Clinic, and can tell you (by email or text) of changes to your treatment pathway.

If you are a Patient, once you have created your account, the app shows you information about your treatment. We will also use the app to ask you to complete questionnaires about your health and document your progress through your treatment, and the answers will be shared with your clinicians. The information will be looked at by members of your healthcare team and shared with other members of the team, if necessary.

If you are a Carer, once you have created your account, we will also use the app to ask you to complete questionnaires about your role as a Carer, and the answers will be shared with those responsible for the Patient's care.

# Information entered by clinicians

Information may be entered by a clinician, in the form of additional data or messages directed to you. Such information will only be shared with you or those responsible for Patient care.

# Further technical information collected

The app also collects technical information about:

- the type of computer/tablet/smartphone you are using,
- the browser or app version you are using, and
- how you use the app.

All of this technical information is stored anonymously – none of it can later be tracked back to you – and is used only to improve the app. Because of the way that the internet works, the app also collects your mobile device unique ID and/or the IP address of your computer. This information will be used only to solve technical problems and is deleted after a few days.

# Who is the information shared with?

The information you (the Patient or Carer) enter into the app is shared only with those responsible for Patient care, i.e. clinicians in the care team. Information entered by a Patient will not be seen or shared with a Carer without their consent, and vice versa.

If you are a Carer, your account will be linked to the patient's records in MyPathway, but not to any of your medical information. Only information you chose to share with the care team will be available and no information will be shared with the Patient without your consent. The care team may discuss the information you provide with you. They may share it with other health care professionals, but only if you give your consent. They may only share it with other health care

professionals (such as your GP) without your consent if they believe you, or someone else is at risk of very serious harm, although they would seek to talk to you about this before they share this information.

The computer system administrators also have access to enable them to fix technical difficulties; all such accesses are logged and reviewed.

Your information might also be shared anonymously (with your personal details removed) and/or combined with information from other patients, with other organisations, in order to improve the care provided to, and experience of, other patients. Anonymous or coded data may be used for research purposes but only with appropriate Ethical approvals and consent in place.

The technical information about your use of the app is shared anonymously with the app development team so that they can improve the app.

# Information security

MyPathway has been developed, and is maintained, by MyPathway Solutions Ltd, a VitalHub UK Company: a company that is accredited to process NHS patient information securely. It has been approved by the Beaumont Hospital Data Protection Officer. MyPathway uses a small number of carefully selected system providers:

- MyPathway stores information on computer servers located at an NHS-accredited data centre in England operated by AWS Ltd. These servers exchange data with Beaumont Hospital computer systems using an encrypted internet connection
- MyPathway uses a MailJet SAS, a French company, to securely and reliably deliver email notifications to users
- MyPathway uses Google Firebase for service improvement, URL shortening, and Push notifications
- MyPathway uses Google reCaptcha on some forms to verify that the user is a human being

The MyPathway servers communicate with your browser, or the MyPathway app installed on your smartphone or tablet over the internet using a secure, encrypted (https) connection – the same security technology as when you browse a secure website.

If you are using a browser to use MyPathway, no information is stored on the computer after you logout and close the browser.

If you are using the MyPathway app installed on your device (smartphone or tablet), your information is encrypted and stored on your device so that you have access to it even without an internet connection. You are strongly recommended to set a screen lock on your device to prevent someone else viewing your information; as long as you do this, your data is protected by the hardware security functions within your device.

## Data retention

MyPathway Solutions Ltd, a VitalHub UK Company as a data processor will only process the data (including retaining it) as instructed by Beaumont Hospital, and all data will be securely deleted from MyPathway when our contract with Beaumont Hospital terminates (with a copy being securely transferred to Beaumont prior to deletion if they request).The clinical information you

enter will be stored as part of your medical record and managed as such in line with GDPR requirements.

## Your consent and your rights

By accepting the invitation and signing-in to the MyPathway app, you are consenting to the use of your data as described above.

You are entitled to a copy of all information about you held within the app, and to have any incorrect information corrected. If, having registered to use the app, you later decide that you no-longer wish to use it, you are also entitled to have your account removed – this will not affect your health record stored in the main Beaumont Hospital computer systems, or the treatment that we offer you. In either case, please contact:

Prof Orla Hardiman,

Department of Neurology,

Beaumont Hospital.

01-8092174

## Your right to file a complaint

If you feel that we have not dealt with your requests properly, or you have other concerns about the way in which we are using your personal information, you can contact the Data Protection Officer, Beaumont Hospital:

Mark Graham,

Data Protection Officer,

Beaumont Hospital,

Dublin9

dpo@beaumont.ie