

MS and My Medical Record

Introduction

NHS neurological care can be fragmented, with barriers to access and communication and little integrated care management. Caring for people with Multiple Sclerosis (pwMS) is becoming more complex with the rise of Disease Modifying Treatments (DMTs) and the growing number of patients. Available resources are limited (GEMMSS Report 2016).

The Wessex Multiple Sclerosis (MS) Service provides care for a widespread region with over 4,500 MS patients (NHIS 2016). The number of patients continues to grow, with approximately 300 new patients/year.

My Medical Record (MyMR) is a digital platform (patient held record) available to patients of the University Hospital of Southampton (UHS). It has been developed by the Trust to

- Provide access to information for patients, and acute and community teams 24/7
- Enable co production of health goals and outcomes from both clinical and patient perspectives
- Provide a research evidence base for improving care planning through outcome measures, health questionnaires and research studies

Objective

The MS team worked with the project and IT teams to develop the MyMR platform to ensure that it met the needs of pwMS and was a useful and sustainable digital tool within the healthcare team.

We aimed to develop the platform to;

- Empower pwMS to engage with their healthcare teams across acute and community care
- Support pwMS in developing self-management skills and goal setting
- Enable staff to support their current and future caseloads safely and effectively

Service development

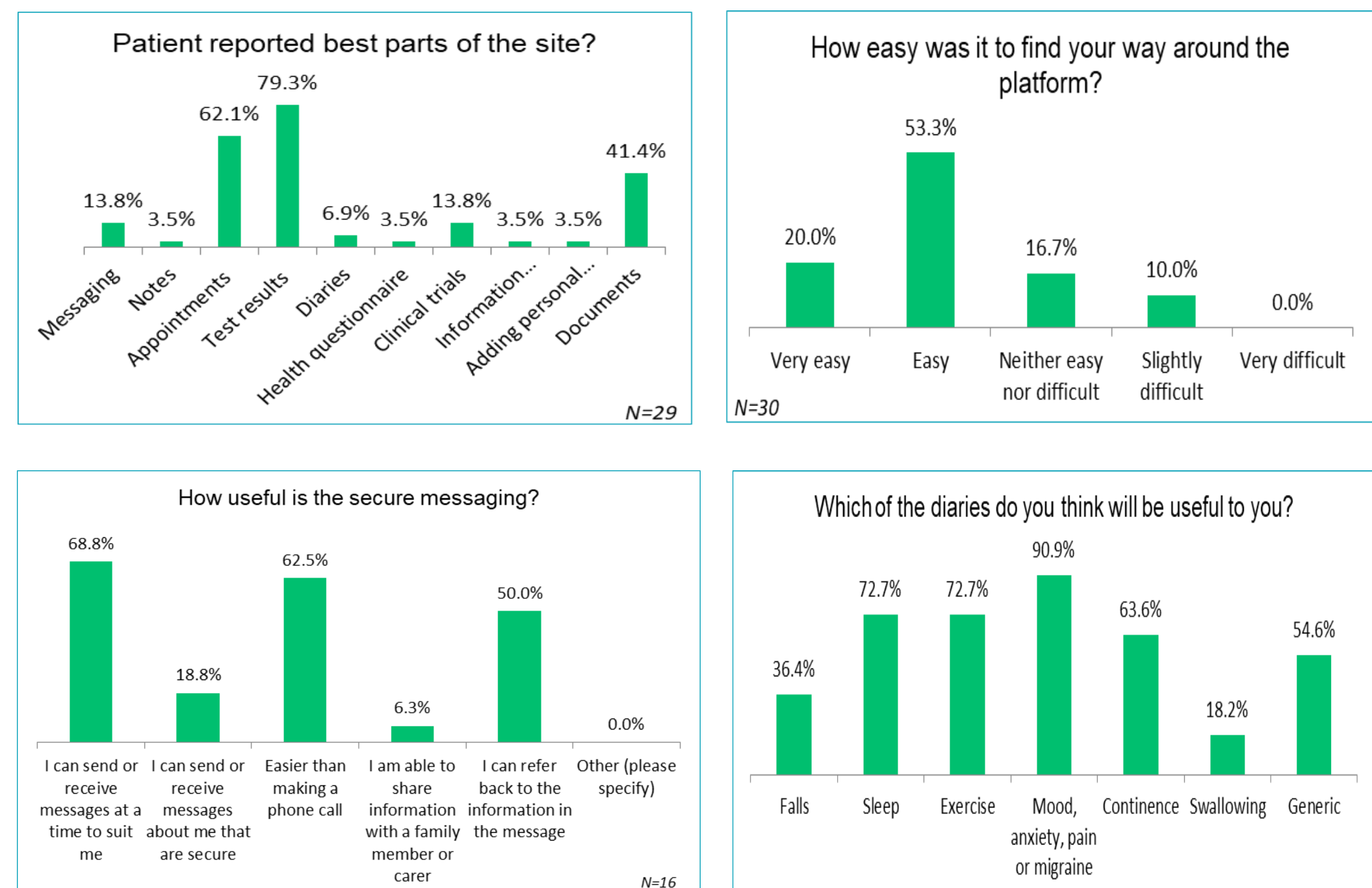
My Medical Record is established in a number of pathways in the Trust. With funding from the Health Foundation, a cross organisational project team was created to spread the platform into five key neurological pathways including Multiple Sclerosis.

Members of the project team included consultant neurologists, MS nurse specialists, IT developers and Quality leads. We also included therapists from the community neurological rehabilitation team to ensure that the platform would support patients along their whole care journey.

The team worked together to develop platform functionality that would be useful to people with MS

Patient focus groups were held as part of the development project. In the development phase patients were asked if they thought the platform would be useful and how it could support them to manage their condition. Following the launch of the platform a patient satisfaction survey was carried out

Figure 2: Patient feedback charts



Results

The MS My Medical Platform went live in August 2018 and over 580 patients are registered and using the platform.

People with MS can now

- Access their clinical letters and appointment bookings
- Monitor their own blood results
- Digitally access MS information and affiliated MS charity links all in once place
- Securely message their MS teams in the acute and community setting improving access to care teams between appointments
- Upload their information and share with other providers, families and GPs
- Complete new online diaries and health questionnaires noting changes in their condition to share with their clinical care teams
- Co-produce online care plans to include personalised goal setting
- Register for local research studies via the site

Feedback from a patient survey showed

- patients immediately valued MyMR functionality enabling them to manage practical aspects of their condition e.g. copies of clinical letters, seeing and changing upcoming appointments, directly viewing test results
- that in the longer term the added functionality would help them communicate with their care teams, understand their condition and improve their self-management e.g. care plans, note making diaries keeping

The MS team routinely ask patients to contact them via the messaging system in MyMR in preference to phone or staff email messages. This allows better message monitoring, with the ability to save messages directly to the patient clinical record where clinically relevant.

Patients with MS in the community are now also working with therapists to develop care plans and set goals for their ongoing care and developing self-management.

Conclusions

This is an exciting project which has demonstrated that new digital technology can be used to alter the way we provide care for people with multiple sclerosis. Staff teams have been able to incorporate the platform into their routine work and patients are engaged and using it to improve their self-management and communication with care teams.

Next Steps

The platform is a key vehicle for the Trust to transform the delivery of outpatient services and provide the right care at the right time. The team are continuing to

- register all patients in the Wessex MS service on the platform
- add additional content to the platform ensuring that it remains current and useful
- add additional health outcomes measures specifically for those with MS

The next phase of the project will focus on development to help the MS team to support and monitor patients on DMT's. The goal is to get the information and care patients need and ultimately monitor patients safely.

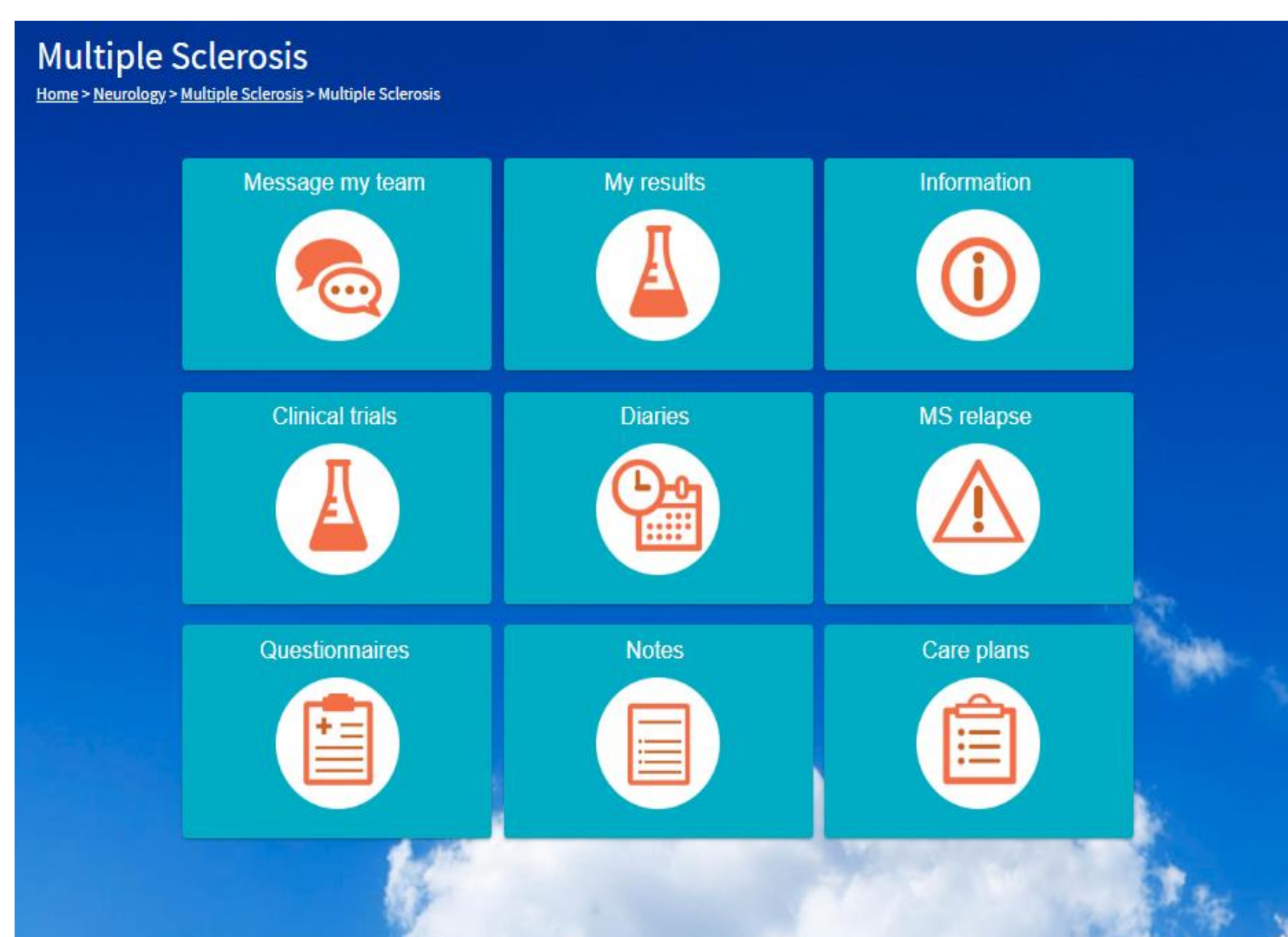


Figure 1: My medical Record MS home page

References:

- Kipps, C. Et al, Wessex Strategic Clinical Network Neurology Intelligence Report 2015
Mynors, G. Et al, MS Specialist Nursing in the UK 2016: Report on progress towards equitable provision