

## QuDoS Multiple sclerosis: NHS case studies 2019 Innovation in Digital Services

### Your name, job title and centre

UHS MS Team, UHS My Medical Record team and NIHR CLAHRC Wessex

### Project / initiative name

My Medical Record

### Project start date

Launch: August 2018



### Challenge

1. NHS neurological care can be fragmented, with barriers to access and communication.
2. Caring for people with MS is complex, with an increasing number of disease-modifying drugs (DMDs) and multi-disciplinary input.
3. Empowering people to develop self-management skills and set their own goals can boost outcomes.
4. Every year, we have almost 300 new patients, yet the staff numbers are not increasing. This is the same across the country – we simply do not have enough clinic spaces and appointments to see all our patients.

### Solution

- My Medical Record is a digital patient-held record available to patients of the University Hospital of Southampton (UHS). It was first developed for cancer patients.
- It gives patients access to their clinical letters, appointments and blood results, and provides access to healthcare teams. It enables the coproduction of health goals and provides a research evidence base for improving care planning.
- Working collaboratively, the UHS MS Team, UHS My Medical Record team and NIHR CLAHRC Wessex, with the backing of the Neurology Alliance, adapted My Medical Record for MS.

- The project was funded by the Health Foundation.
- The project team included consultant neurologists, MS nurse specialists, IT developers and quality leads. Therapists from the community neurological rehabilitation team were also involved, to make sure the platform supported patients throughout the disease trajectory.
- Patient focus groups were held to inform the development of the MS-specific platform. They were asked if they thought it would be useful and how they thought it might support them to manage their condition.
- Care plans, basic disease information and what to do in the event of a relapse were added to the MS-specific platform.
- My Medical Record is already available in other conditions. This means there were no concerns over ethics, compliance or data protection as the platform has already been approved.
- Since the platform was launched in August 2018, every patient seen in clinic has been offered access to My Medical Record.
- A patient satisfaction survey was carried out after the launch of the platform.

## Results

As of October 2019, more than 600 patients have registered and are using the platform. They can now:

- Monitor their own blood results.
- Access their clinical letters and appointment bookings.
- Digitally access MS information and affiliated MS charity links.
- 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 online diaries and health questionnaires noting changes in their condition which they can share with their clinical care teams.
- Co-produce online care plans to include personalised goal setting.
- Register for local research studies via the site.
- The MS team now routinely ask patients to contact them via the messaging system rather than by phone or email. This allows better message monitoring, and the team can save messages directly to the patient clinical record when clinically relevant.

Feedback from a patient survey showed:

- patients immediately valued the fact that the platform allowed them to manage practical aspects of their condition through providing copies of clinical letters, being able to access and change upcoming appointments, and see their test results
- they felt that in the longer term, added functionality would help them to communicate with their care teams, understand their condition and, through elements such as care plans and diaries, improve their self-management.

## Next steps

The next phase of the project will focus on helping the MS team to support and monitor patients on DMDs.

## What was the biggest challenge(s)?

The biggest challenge was the time it took to register patients. That includes the time it took to explain the concept to people and for staff to physically set people up on the system. For data protection reasons, team members had to register their own patients, and this took a little time at the start.

## How did you overcome the challenge(s)?

We found better ways to describe the system. When someone has children, for example, we liken it to the physical records pregnant women are given. We also have a leaflet about data protection. Setting people up on the system got quicker with practice.

## What would be your advice to others wanting to replicate this project?

- Make connections with your IT team, they will be your biggest champions on a project like this.
- Contact the My Medical Record team at UHS who will be more than happy to meet your team, together with the other stakeholders, to demonstrate the platform
- Find a handful of your patients who would be willing to champion this for your service

## Testimonial quote

“  
“  
**from a  
patient**

I am able to stay connected to my MS team via MyMR even though I live in the Falklands. I still see them face-to-face yearly, which is a feat on its own, but I am confident that I can access them when I need them in between. I can also download my blood monitoring on MyMR so my team can advise my local team here if needed.”

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