# Innovating for Improvement

# Neuro LTC: Online integrated care plan

University Hospital of Southampton NHS Foundation Trust in partnership with Solent NHS Trust





#### About the project

Project title: Neuro LTC: Online integrated care plan

Lead organisation: University Hospital of Southampton NHS Foundation Trust

Partner organisation(s): Solent NHS Trust

#### **Project lead:**

Dr Chris Kipps,

# Project team:

Rachel Chappell, Carl Adams, Kev Hamer, Sallyann Smith, Natalie Steel, Jo Watts, Hayden Kirk, Sarah Fern

#### Contents

About the project	2
Part 1: Abstract	3
Part 2: Progress and outcomes	4
Part 3: Cost impact	9
Part 4: Learning from your project	11
Part 5: Sustainability and spread	16
Appendix 1: Resources and appendices	20

#### Part 1: Abstract

People with long term neurological conditions (Neuro LTC) often have complex needs that fluctuate over time. NHS care in neurological pathways can be fragmented, with patients and their carers reporting barriers to access, poor communication and care that lacks integration.

Digital is an opportunity to do things differently.

This project developed an online platform to support and improve healthcare self-management, care planning, and outcomes measurement for local patients living with a neurological condition.

The platform enables a new level of information sharing, co-production and communication including:

- secure 24/7 online access from any location or device
- shared information visible to patients, acute and community teams
- co-produced, interactive health goal development
- ability to monitor progress from both patient and healthcare staff perspective
- evidence base in place to improve care planning through outcome measures, health questionnaires and research studies

The project demonstrated that the online platform was

- technically feasible and achievable
- welcomed by patients who found it useful
- able to be incorporated into existing clinical workflow

The success of the project provides a framework for spread across remaining neurological pathways, and provides the capability to transform outpatient care in long-term conditions.

"I am really pleased to see this development which will improve communication between the patient and their teams in real time and provide a platform for information sharing, updates and advice"

Clinical Nurse Specialist

# Part 2: Progress and outcomes

#### **Project aims**

My Medical Record (MyMR) is the University Hospital of Southampton selfmanagement platform designed to put patients at the centre of their care. Our project adopted, adapted and innovated new MyMR functionality aimed at people receiving neurological care in acute and community settings.

#### Which pathways?

We focussed on pilot conditions that illustrated a range of clinical pathways, demographic factors, clinical teams and locations, namely:

- Multiple sclerosis (MS)
- Epilepsy
- Huntington's disease (HD)
- Parkinson's Disease (PD)
- Motor Neurone Disease (MND)

#### **Building the platform**

#### Adopt – clinic letters, test results and appointments

Patient letters, appointments and test results routinely flow into My Medical Record. Individuals can add personal data to the site, providing a single source of often requested data which can be shared with healthcare staff.

# Adapt – Messaging, information, diaries and health outcomes

The platform supports secure messaging between patients and clinical teams offering:

- direct access to relevant care teams when needed
- a secure environment for discussion of clinical concerns
- one-click mechanism to save message content directly into a patient record

We worked with teams to ensure that this functionality was incorporated into clinical workflow.

Each team identified condition-specific information and resource links, and wrote a series of FAQ documents to make the sites relevant and useful.

We linked to website resources we had previously developed listing clinical research trials and local neurological resources.

New templates (diaries) were designed to support capture of useful information on events that occur for people with long-term neurological conditions, including:

- Falls
- Sleep
- Exercise
- Swallowing
- Mood, anxiety and pain
- Continence

Health outcome questionnaires were added to the site to help measure outcomes including health status and quality of life. The EQ5D allows comparison across a range of other long-term conditions, and supports economic evaluation of care processes.

#### Innovate – Care plans

A key innovation of this project was to create online care plans. Currently, these are written in a variety of templates, seldom show outcomes, and are not easily shared across teams.

Working digitally was an opportunity to resolve some of these challenges.

We used literature reviews, best practice and local knowledge to create the care planning module; this supports:

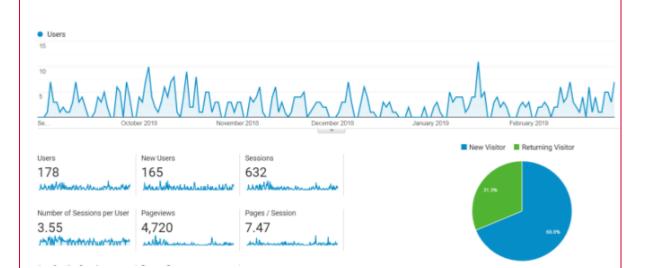
- defined goal areas relevant to people with neurological conditions
- ability to select and personalise goals
- recording of agreed actions to support goal achievement
- agreed timescales for review
- opportunity for reflection on goal achievement and impact
- recording of clinical outcomes

# Site Usage

By March 2019 all 5 neurology sections of My Medical Record were live with 212 patients registered via both the acute and community teams.

Site	Registered patients
Multiple Sclerosis	178
Huntington's Disease	3
Parkinson's Disease	0
Motor Neurone Disease	17
Epilepsy	14
Total	212

Over 4720 pages have been viewed since August with over 68% of patients visiting the platform more than once.



All registered patients were surveyed to give feedback on the platform. Overall patients liked the site and agreed that it would support them to manage their condition and be more involved in their care.

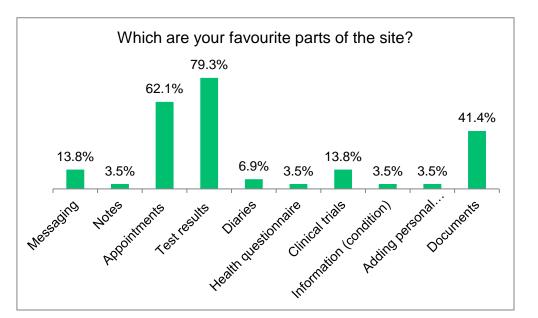
'The most exciting part of the platform for me was....

.....'seeing all my appointments, results and information in one place that is easy to access'

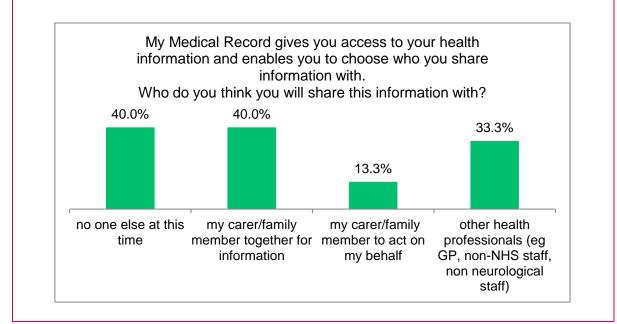
......'Being able to see blood results without having to contact MS team'

- patient survey

When asked to identify the parts of the site they liked most, users tended to select functionality that was of immediate practical relevance (appointments, test results and clinical documents). Messaging and information functions were also appreciated, but may have been less immediately relevant.



One of the key aims was to improve information provision to patient users and to allow them to share it with others; the responses indicate that this is valued for current and future needs.



# Staff feedback

Staff were positive about the platform, keen to engage with the project team and wanted to identify areas of development relevant to their patient groups e.g. seizure video uploads, expansion of site into younger onset dementia.

"My Medial record will put patients at the center of their care by having all the information in one place...allows patients to have their information as they work with a range of services"

Community neurology physiotherapist

"My patient group are quite young and proactive and quite involved in their care MyMR gives them a bit more recourse to support them in being independent to look after their MS"

Specialist MS nurse (community)

"Ideal opportunity and platform through which the patient can communicate with their service better and therefore I can communicate with them......everything is in one place"

Specialist Huntington's disease nurse (acute)

"A practical example of how organisations can work together to do something for the good of the patients and the staff working within them...breakdown some of the barriers across the organization and really put the patient at the center of what we do"

Community Clinical Services Manager

# **Online Care Plan Pilot**

The care plan module was a bespoke development and was completed in January 2019. This is being implemented in a community team setting.

Benefits identified in a case study include:

- Access to all clinic documents in one place
- Ability to review care plan on smartphone
- Co-produced and updated care plan (patient and physiotherapist)
- Review date set
- Patient and community therapist could see upcoming out-patient appointments and discussed areas that could be flagged at next consultant review
- PDF was saved to clinical record reducing admin time

#### Part 3: Cost impact

**Neurological Services**Neurological services are typically funded through a combination of Clinical Commissioning Group (CCG) and Specialised Commissioning of NHS services. This supports both inpatient and outpatient care. Neurology services are primarily delivered on an outpatient basis.

My Medical Record, the University Hospital Southampton self-management platform has been developed by the IT department and is currently supported by the Global Digital Exemplar project, for which Southampton is a site.

The platform has supported self-management across a range of conditions, and during this project created bespoke sites for a range of neurological conditions using existing functionality.

We also developed new functionality (event-specific diaries and care planning) to support the ambition of the project to enable integrated care planning across locations. Care in these conditions often lacks cohesion across the pathway. Over time, development of the platform offers a way to improve care through integration across providers in different locations, and measuring the outcome.

#### Cost Impact

The full cost benefit from this project is yet to be realised (or measured). It will largely derive from the ability of the platform to:

- Streamline care provision by identifying and focussing on those with the greatest need for support (risk stratification)
- Streamline care processes: nurses and therapists using MyMR are able to manage patient case loads in a more time efficient manner
- Reduce outpatient follow-up requirements; this is a major cost to the NHS, yet it remains unclear what value it provides. The MyMR platform offers an opportunity to reduce this cost through replacing unnecessary appointments, and to identify where in the pathway healthcare value is offered; and then change process around it
- Build a cohort of individuals with documented intervention to assess outcomes, and therefore focus future support on the most effective interventions
- Reduce administrative costs: outpatient paper letters, missed appointments; patient information leaflets (paper and postage)

 Reduce patient costs (less travel – environmental; more efficient process – less time and inconvenience)

A full economic evaluation has not been performed, but the platform supports outcomes data (e.g. EQ5D) which has been extensively used to model cost-effectiveness in long-term conditions. This is currently being collected.

The platform requires further investment at this point to realise the potential costsaving. The funding from the Health Foundation has developed the functionality sufficiently for it to accelerate the process in clinical care and is now live. Further evaluation is in progress.

# Part 4: Learning from your project

#### **Project Achievements**

- Successful development and launch of neurology self-management platform across 5 conditions, linking acute and community care
- 212 patients online. A major IT upgrade delayed initial launch; registrations now growing rapidly.
- Excellent feedback: patients say site is useful and will become more useful
- Staff highly engaged in the project, with major contribution to development of sites and registration
- New care planning functionality supporting clinical workflow and enabling co-production between patients and healthcare staff
- Mechanism for assessing outcomes across a large cohort; will provide crucial data for service improvement
- Platform will support a step-change in care delivery

#### **Clinical Variation**

Condition sites launched in 2018 (Aug-Dec). Teams adopted the platform and introduced patients to suit clinical workflows, by:

- sharing information and registering patients
- adding information about joining platform to clinic letters
- emailing information to identify interested patients

Variation was seen between conditions:

- The MS team was the first to go live, were quick to see the benefit for clinical process, and have had most time for accruals. A highly motivated champion, and support for core business function (test results) was extremely helpful.
- The epilepsy team has high numbers of patients under age 18 but platform focused on adult epilepsy. Under 18's will be considered in future development
- Caseload in Huntington's disease is small, but highly complex. Uptake is slow, but allows us to focus on specific needs in this group.

- Creation of delegate access (for carers and families) is incomplete, and is needed where carers are highly involved.
- Slow uptake in Parkinson's disease; reasons are unclear but may include levels of digital literacy
- In MND, despite small numbers and rapid disease progression, care team encouraged by positive patient reception; sign-up rapid, and team keen to expand the site into routine workflow
- A mixed caseload is seen in community clinics; a generic site will be introduced to support this
- Data from UHS, but not the community trust, flows directly into My Medical Record. This is needed to enable the community team to optimize use of digital care plans
- Dashboards, outcome indicators and risk stratification tools are in development and will further increase clinical utility

# Complexity as a Challenge and as an Enabler

To generate transformational change in healthcare, ambitious steps are needed. However, there may be many more steps in the process than are apparent at the start, or visible at the end.

This project needed to be bold to achieve critical mass, yet was complex and management was challenging. We attempted to separate areas that:

- could stand alone
- were dependent or interlinked
- were the minimum viable product (MVP) for release
- needed high completed functionality prior to final release
- had teams ready to move forward at pace
- had teams needing more support

We adapted the project plan to slot in a different work packages as circumstances changed to maintain a forward trajectory even when some areas stalled.

#### **Project enablers**

The digital environment is around us, and we all use it. There is an expectation for the same to occur in healthcare. The NHS is responding.

#### Staff and Patient buy in – Selling the Dream

We had to sell a dream before we had a product.

Our biggest initial challenge was promoting the project to busy staff teams who were concerned about the impact on their workflow. Building relationships and explaining the benefits was key. We needed involvement to ensure traction and sustainability.

#### Challenges

Digital development is exciting, but not easy. Software development is expensive and IT infrastructure is often already established. There was a need to constantly adapt while moving forwards to deliver. Agile processes phasing developments, pushing in short bursts, quick wins and use of opportunistic levers were vital.

Technical teams and clinical teams work in different parts of the system and can speak separate languages. Some clinical ideas are not technically feasible, and some technical solutions will never work in clinical practice. This is important to learn early.

#### **Unexpected challenges**

- Major IT system upgrade was necessary shortly after project launch creating delay
- Project team used this time to phase development and push forward on areas not dependent on IT

# Learning on introducing and sustaining innovations in the NHS?

What will you – personally, as a team or as an organisation – take away from this project?

- Large scale ambitious projects are hard work. For every planned step, numerous unplanned steps are needed. Even when everyone is agreed on the vision the changing environment creates diversions and challenges.
- A dedicated project manager to act as a point of focus is essential to ensure project oversight, communication, challenges identified, and resolution implemented so that progress is maintained.
- The project manager needs a level of organisational independence and ability to work seamlessly between teams and cultures (IT, clinical staff, patient groups, different organisations)
- Understanding behaviour change as well as delivering an agreed product is vital. Human factors have a huge influence.

What would you have valued knowing at the start? How might you approach future projects differently as a result?

- Stakeholders with vision, and stakeholders who make things happen, are key but may not be the same people.
- Project benefits, short and longer term, should be clearly articulated and refreshed regularly.
- IT stakeholders divided into those with strategic vision and those who carried out day-to-day operational tasks. In future we would try to ensure we consistently communicated well with both groups.
- This was a large scale, long term change project, not a software development project.

What are the key things others would need to know / put in place if they were to adopt your intervention or implement a similar project?

- Links to other projects are useful but care is needed to maintain independence and authority to move forward independently. Be opportunistic and network.
- A co-productive ethos is vital when working with varied stakeholders with differing agendas and processes.

• Once you need a specialist skill in any project (software development) your ability to influence timescales and delivery is diminished. Success needs to be defined in terms of a common goal for all.

"Anything that is one step in real life can be 100 steps on a digital pathway" Consultant Neurologist and Project Clinical Lead Part 5: Sustainability and spread

We proved the platform was technically achievable, acceptable to patients with neurological conditions, could be incorporated into staff workflow, and that there was ongoing enthusiasm for the project.

The NHS 10 Year Plan was launched in January 2019 with key themes including:

- giving people more control over their own health
- making better use of digital technology and developing digital out-patient care
- using technology to free up staff time, making the most of their skills and focus on patient care
- breaking down barriers between care organisations and promoting joined up care
- using research and innovation to drive future outcomes improvement

The platform is a key tool for Southampton and Solent Trusts to support these themes.

The ongoing development of My Medical Record will continue as part of the Global Digital Exemplar funding. We have also submitted an NIHR Technology Innovation application to evaluate My Medical Record (Neuro) implementation, and trial different implementation options to improve uptake and engagement of the platform.

Other funding opportunities will also be explored to fast track the areas described below

# **Empowering Patients**

Patients have registered and started to engage with the platform. To build on this the platform needs to present fresh and engaging material and streamlined functionality.

Next steps:

- development of short videos accessible from the site to demonstrate how patients might best use it to manage their condition
- development of case studies and real-life examples to demonstrate how 'a patient like me' has improved their self-management
- Working with the clinical teams to understand aspects of functionality which may improve usability for specific patient groups

#### Breaking down organisational barriers

Patients are seen by many healthcare professionals during the course of their long-term condition. Accessing their health data, and the ability to share this with professionals who are helping them with their care, places patients back at the center of their care.

To further support this, we intend to:

- Work to understand and improve data flows to and from the platform to allow further integration of the care pathway
- Data flows of interest include clinical records from other Trusts, sharing of care plans into the clinical record, integration of third party app information and sensor technology into the platform

# Using Digital to Change Care

Digital technology allows us to deliver care differently delivery, and to appropriately target care for those that need it. This frees staff to focus on more complex intervention and care planning.

Next steps:

- creation of a generic neurology platform providing access to all neurological conditions
- routine registration of all patients accessing neurological services at University Hospital Southampton and Solent NHS Trust
- development of delegate access allowing all patients to nominate carer and family access to the platform
- work with neurology business managers to move administration processes to the platform – initially reducing postage of clinic letters which can be offered through the platform
- highlighting successes of this project will be used to generate further enthusiasm across clinical groups and development team
- learning will be shared with the Trust to inform the aim of re-imagining outpatient appointments and developing virtual clinical care pathways

# **Developing a Research Platform**

An evidence base is crucial for implementation of new service models. The My Medical Record platform provides an opportunity to direct patients to appropriate clinical trials of the platform itself, and also provide information on implementation of models of self-management.

Next steps:

• a further grant application has been submitted to NHIR to research the uptake, utility and retention of the platform

The platform is of interest to the work on care planning by the Neurosciences Clinical Reference Group and Neurological Alliance. It has been presented at meetings of these groups, and further discussions are underway. There has been discussion about the use of the platform across UK Neurosciences Centres which is ongoing.

We have presented this work to the West Hampshire Clinical Commissioning Group, and discussed use of the platform with the Hampshire IOW STP. The ongoing work will be facilitated within the Wessex Clinical Network and will be actively supported by the Wessex NIHR ARC.

We are hoping to extend this project with further research grants which will allow the care planning module to be evaluated; this would be supported by the Wessex Clinical Research Network.

The work has been supported within the Trust and the Outpatient transformation agenda. It will be embedded in 2019-20 cost improvement plans.

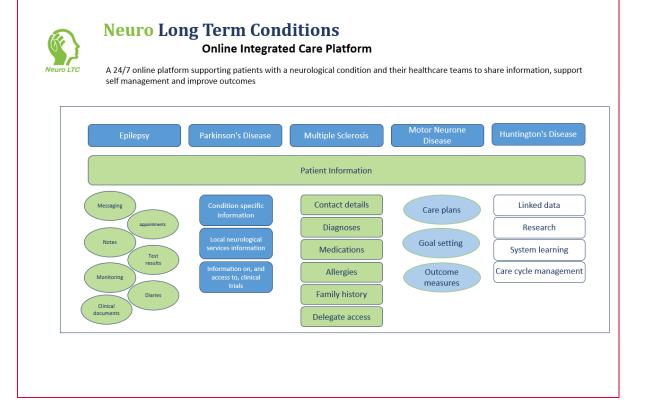
# Appendix 1: Resources and appendices

Please attach any leaflets, posters, presentations, media coverage, blogs etc. you feel would be beneficial to share with others.

Note that, as we would want to upload these onto the Health Foundation website, we ask that you are discerning with additional material provided.

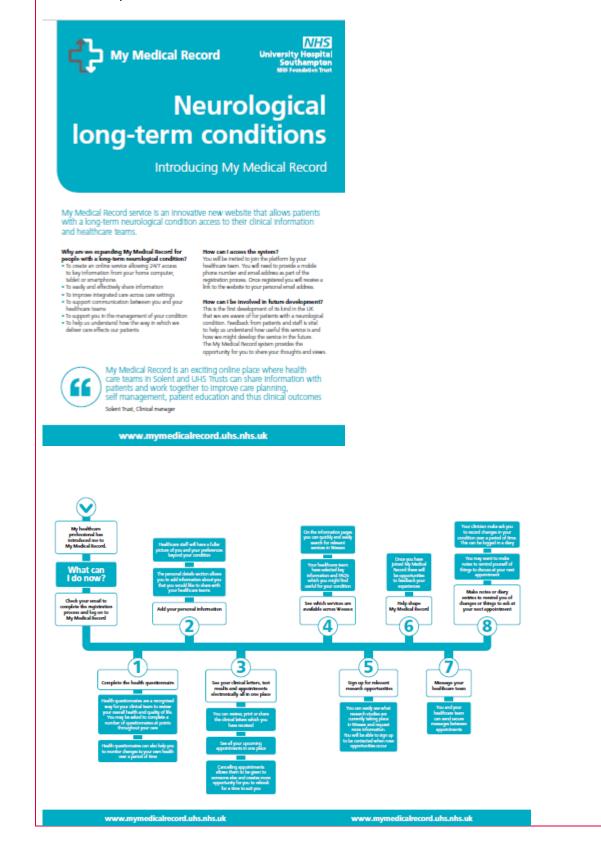
# Neurology My Medical record - Eco system diagram

Schematic diagram of the Neuro LTC platform showing the functionality and use of the platform



#### **New Patient leaflet**

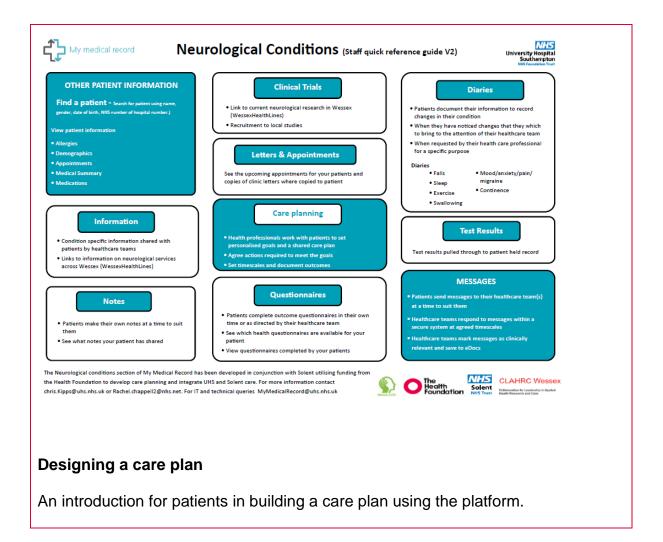
Leaflet produced to support the introduction of patients to the platform. The leaflet give general information and suggested tasks that a newly registered patient might like to complete.





# Staff quick guide to Neuro MyMR functionality

A short guide for staff teams to understand how the functionality of the platform links to their work flow.





- understand your own health
- understand discussions with your healthcare team
  stay as independent as possible

- do the things you enjoy
  identify the type of support you need

We have designed the neurology My Medical Record Care Plan to help you and your healthcare teams to design your care plan and achieve your goals.

You +	Your healthcare My Medica		Your online personalised CARE PLAN
	professionals Record		
Who	Action	Suggestions	
2	Choose which goal area to focus your care plan on.	Choose a goal area that matters to you and that you want to improve.	
2	You can choose sub goal areas within your main goal area.	Your main goal could be to walk further and your sub goal could be to work on your balance.	
2	Describe the goal in your own words	For example, 'I want to be able to walk to the corner shop so that I can buy fresh milk.'	
-		Or, 'I want to wake up feeling refreshed so that I can improve my activities.'	
	You and your healthcare teams can discuss the actions you need to do to achieve your care plan goals.	For example, your therapist or nurse might suggest some physiotherapy or a review of your medication.	
	You can then agree on a timescale and a date to review the care plan actions.	For example, you may choose to complete an action within one month or you may agree that it will take	
	You or your healthcare professional can add notes on the progress of your plan.	three months to se	e any changes.
	You and your healthcare teams can work together to decide when your care plan goal has been completed. You will both have a place to describe how you feel the goal has been achieved.	For example, 'I can now walk to the shops and am increasing my stamina every day.'	
Extra features	deniered.		
those you an	cal Record, you can see all your current g e working on.		
You can prin with others.	t out your care plan to remind you which	areas you are worki	ing on or to share