

Framework for Neurological Care 2020-2025 Funded Projects



Scottish Government
Riaghaltas na h-Alba
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FINAL REPORT

Project Title: Tailored Talks Neurological Framework

Overall Aim: *Initiation of Phase 1 of a project to create a library of content, enabling clinicians across 14 neurological pathways to create Tailored Talks for their patients. Also to develop the Tailored Talks system to include feedback and analytics, and html slide builder functionality for use by clinical staff.*

Department/NHS Board: A collaborative project including:

Chest Heart & Stroke Scotland



NHS Lothian/Health Innovation SE Scotland



University of Edinburgh



Pogo Studio



Edinburgh Headway Group



Project Lead: Prof Martin Dennis

Project Start Date: Nov 1st 2020

Project End Date: Phase 1 funding -31/03/2021, Phase 2 funding 31/03/2022

Report Date: 31st Aug 2022

Introduction

Currently, information for patients with neurological conditions is shared by clinicians verbally, but usually with no audio-visual materials. Patients may receive condition specific printed information leaflets, often produced by third sector organisations. They may also be invited to access online information provided by the NHS (e.g. NHS Inform) or third sector organisations. There are a number of disadvantages to this approach, as follows:

- Much of this information is generic and not tailored to the individual patient's specific needs.
- It relies on patients being able to identify that information which is relevant to them.
- Leaflets and on line materials may contain irrelevant information which does not apply to the patient.

Clinicians in the University of Edinburgh in partnership with NHS Lothian (Health Innovation SE Scotland <https://hises.edinburghbioquarter.com/>), Chest Heart & Stroke Scotland, and Pogo Studio (POGO) <https://pogodigitalhealth.com/> and Edinburgh Headway Group have developed Tailored Talks. Tailored Talks is an innovative digital presentation platform which can ensure that only information relevant to the individual is shared. Because the information is digital it can be shared by a wide range of methods in both face-to-face, or remote consultations.

Tailored Talks is currently used to provide tailored information to patients who have required ITU treatment for COVID 19 during their hospital admission and in the community by staff from NHS Lothian and CHSS. It enables tailored information, including written information, web links and videos to be shared on screen, on paper or by email, and it can be shared with nominated family members or carers. The content is regularly updated to ensure it remains correct, relevant and accurate,

It provides a permanent record of the information discussed during consultations, which the patient and their carers can revisit as often as they wish via a patient portal.

Future planned developments of Tailored Talks will allow the information to be delivered in different languages and made accessible for patients with visual impairments by allowing text to be read aloud.

This project

This project was funded by the Scottish Government's Neurological Framework for 30 months. The project has delivered on its three main deliverables:

1. Development of the Tailored Talks system to provide to new functions:
 - a. a "dashboard" which collates and presents reports on use. This module is the primary source of the quantitative information included in this report.
 - b. A slide builder which improves the "look for content" function, allows for active hyperlinks to be added to slides which in turn improves the ability for signposting and linking out to other services and resources and in the future to have "read out loud" function for those with visual impairment, and content in multiple languages for those whose first language is not English.
2. Collaboration with specialist clinicians and relevant 3rd sector organisations to develop the content for a wide range of important neurological conditions (see table below) and
3. Offer access to, and training in the use of, Tailored Talks to health and social care staff working with patients with neurological conditions across Scotland.

Our collaboration has produced content covering the following 22 neurological conditions, although we intend that content will gradually expand in response to feedback from users, patients and their families.

Condition	No. of slides (August 2022)
Acquired brain injury	174
Alzheimers disease	20
Bell's palsy	1
Brain tumours	116
Carpal tunnel syndrome	6
Cerebral small vessel disease	10
Cervical spondylosis	5
Epilepsy	99
Functional neurological disorders	60
Huntington's disease	44
Hypnic jerks	2
Meralgia parasthetica	5
Migraine and other headache syndromes	119
Motor neurone disease	27
Multiple sclerosis	54
Myasthenia gravis & muscular dystrophies	196
Notalgia parasthetica	2
Parkinson's disease	35
Sleep paralysis	3
Stroke	644
Ulnar neuropathy	4
Vascular malformations of the brain	74
Total	1700

We had aimed to complete both phases of the project by March 31st 2022. However, because of delays in clinicians and 3rd sector organisations providing and/or approving content due to COVID and other pressures the roll out to neurological services only commenced in April 2022. Also some 3rd sector organisations were hesitant to engage because it had been unclear whether those contributing content would need to ultimately fund their access to Tailored Talks. Hopefully with clarification that they would not need to pay for access will smooth the way to their more active collaboration in the future.

The roll out will therefore continue through to March 2023. This report therefore includes only the progress made to this point (August 31st 2022).

Outcomes

The most important outcome is the provision of high quality information about a wide range of neurological conditions which can be tailored to the needs of individual patients and shared easily. This should in turn improve patient outcomes by facilitating involvement in shared decision making, consent, self-management and help patients access relevant services and support, Good quality information should also improve adherence to treatments. This outcome will depend on the neurological community routinely using Tailored Talks and then we can begin to collate their feedback and use that to further improve the content and platform going forward.

Roll out

Through contacts in each neurology/neurosurgery centre we produced a list of email contacts. In April 2022 we invited 145 individuals (Lothian 60, GG&C 48, Grampian 12 & Tayside 15) to sign up for a free Tailored Talks account. In June we emailed those who had

not responded again. Fifty five (38% of those emailed) individuals have since requested an account. 21 from NHS Lothian, 12 from GG&C, 8 from Grampian, 8 from Tayside, 1 from Lanarkshire & 1 from Forth Valley.

The table below puts the neurological roll out (which started in April 22, into the context of the roll out across NHS Lothian in 2020 (where Tailored talks was developed and first used in COVID, but subsequently in stroke and other services), Chest Heart and Stroke Scotland in 2021, and Stroke services in other NHS Boards (from April 2021).

Organisation	Invited to register	Registered	Logged in	Active in last 8 weeks	Talks shared	Talks viewed
CHSS	38	38	28	8	121	n/a
NHS Lothian (including COVID, stroke & neurology)	228	184	101	34	505	1167
Scottish stroke service (not Lothian)	290	203	104	25	21	79
Neurology services (not Lothian)	61	37	8	4	0	0

Since June 2022 we have offered access to:

- On line user guide developed by POGO
- 6 Youtube training videos developed by POGO (total 18 minutes) –
 - Video 1 – 22 views, Video 2 – 16 views, Video 3 – 8 views, Video 4 – 5 views, Video 5 – 5 views, Video 6 – 8 views
- Eleven weekly live training sessions for groups using TEAMS delivered by POGO staff.
 - 28 individuals have attended at least one of these sessions so far.

In addition Prof Dennis has delivered training sessions to groups of staff including Neurologists in Lothian, Neurology trainees, MND nurses, Stroke nurses, AHPs.

Prof Dennis has demonstrated Tailored talks on two occasions (June and Aug 2022) to the national Stroke Voices Group (set up by the SG Priorities team to feed into the development of the Progressive stroke pathway. The group highlighted the major deficiencies of current models of information sharing and expressed their strong view that patients and families should have access to information tailored for them by a healthcare professional using Tailored Talks.

Next Steps

1. Continue activities to raise awareness of:
 - The realistic medicine agenda including shared decision making.
 - The shortcoming of traditional methods of sharing information with patient and families
 - Tailored Talks amongst healthcare professionals in services which already have access and in those where there maybe a role for Tailored Talks.

Prof Dennis presented Tailored Talks at the annual conferences of UK stroke forum 2021, European stroke organisation 2022, Scottish stroke care audit 2022 and plans to present it at SANS 2022 and UKSF 2022. In Sept we are running a prize draw for all healthcare professionals who tailor talks for patients or families to encourage use.

2. Offering free access to training.
3. In Lothian, Tailored Talks is being developed into an App to deliver care for Long Covid, and in the future for COPD and stroke.
4. There is also ongoing work to use Tailored Talks in the process of gaining formal written consent to treatment (in Oncology) and clinical research.

All healthcare staff working in Lothian, those working for CHSS and those working within NHS Scotland stroke services currently have ongoing access to Tailored Talks through existing agreements between POGO and these parties. Staff in non-Lothian neurological services currently have free access.

Total Amount Funded:

- £105,524 (20/21)
- £68,996 (21/22)

Funding has been fully committed by 31st March 2022 but the information collated in this report is derived from the Dashboard/Reporting system which was developed as part of the Neurological framework project.