NeuroRehabilitation OnLine (N-ROL)
Prof Nick Ward, Benjamin Beare, Dr Catherine Doogan & Prof Alex Leff, UCL.
Emilia Clarke, SameYou
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Talk Transcript – Prof Nick Ward

Hello, I'm **Nick Ward** from the **National Hospital for Neurology and Neurosurgery**, Queen Square in London

I'm here to talk to you about **N-ROL** or the **NeuroRehabilitation OnLine project**.

N-ROL came about in **response** to the **Covid-19 pandemic**.

We realized that patients with stroke or other forms of brain injury would be **discharged home** much **earlier** than **normal** in order to free up acute hospital beds.

Once home it would be **difficult** for the **community rehabilitation teams** to **visit** these patients and as a result, we'd have a large group of people with stroke and brain injury who were **not able to access** the **care** and **treatment** that they need at this **really important early period** after their injury.

So, we talked to the **rehabilitation teams** and we decided to set up **N-ROL** a form of **group online telerehabilitation** where **one** or **two therapists** can work with **groups** of up to **10** or **20 patients**.

These groups provide **support** for both **patients** and for their **carers** and we have set up **groups** that **target** specific problems with **movement**, **communication**, **cognition**, **emotion** and even **fatigue**.

We're aiming to **support** people in their **ongoing recovery** but we also want to provide people with the **motivation** and the **confidence** that they can **achieve the goals** that are important for them.We also want to **reduce** that **sense of social isolation** or **abandonment** that patients often feel when they're discharged home early.

We really want to provide people with the hope that they're going to get the care that they need and that ongoing recovery is possible.

N-ROL is a new way of doing **neurorehabilitation** and we're excited to learn from the process because we think it's going to be important as we move forward.

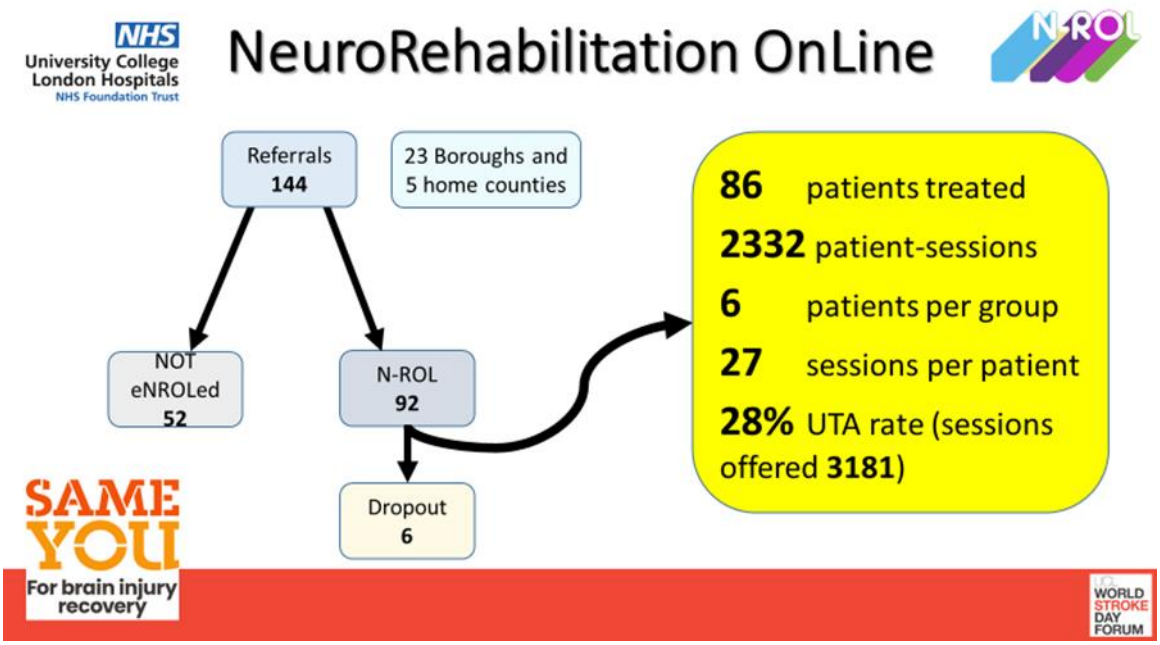
The work has been made possible by the **fundraising of Emilia Clarke's SameYou** charity — and we want to say a big thank you to them and to everybody that's donated in order to support us in this important work. Thank you.

Talk Transcript – Benjamin Beare

Hello my name is **Ben Beare** and I'm a **physiotherapist** and I'm going to talk to you about **NeuroRehabilitation OnLine** or **N-ROL**.

As Professor Nick Ward has just explained, **N-ROL** was set up with the **support** and kind and generous fundraising of the **SameYou charity** who **employed myself** and **Dr Catherine Doogan** to set up an **online service** for people **post stroke** and post brain injury who were affected by the **Covid crisis**.

As the slide below shows you, we received a total of **144 referrals** between the **end of April** and the **end of July 2020** which encompassed **23 London boroughs** and **five home counties**.



All these **potential participants** were then **screened** to ensure they were **appropriate** for an **online service**, but also this enabled us to **triage** them to **different components** of the **service** that were most appropriate to them.

Also, it allowed us to consider **safety considerations** for their **online participation** in **exercise** but also allowed us to **gauge their attitudes** and **understanding** towards different components of their stroke and brain injury. So, we were able to **individualize** and **tailor** the **education components** of our service.

So, in total **92 participants** were **enrolled** and we **completed outcome measures** with these participants.

We completed the **stroke self-efficacy questionnaire** and the **NROLOM**, which was an **outcome measure** developed by the service to **consider components** of the **Covid crisis**.

And **52 people** were **excluded** and I'll talk about those in a second

And unfortunately, of those **92 participants**, **six people** after having outcome measures completed where then **not able to participate** in any component of N-ROL because they either had **significant medical problems** or **family support issues**.

So, we **treated** a total of **86 patients**.

In general, on average **patients** attended a total of **27 sessions** when they were involved in the **N-ROL service** with an on **average group size** of **six patients** per group. Therefore, we provided in total **2332 patient sessions**. We offered **3181** but we had an **unable to attend rate** of **28%**. I'll talk about those reasons in a second.

So, an **important** thing to consider is why some people were **not able to participate** in N-ROL.

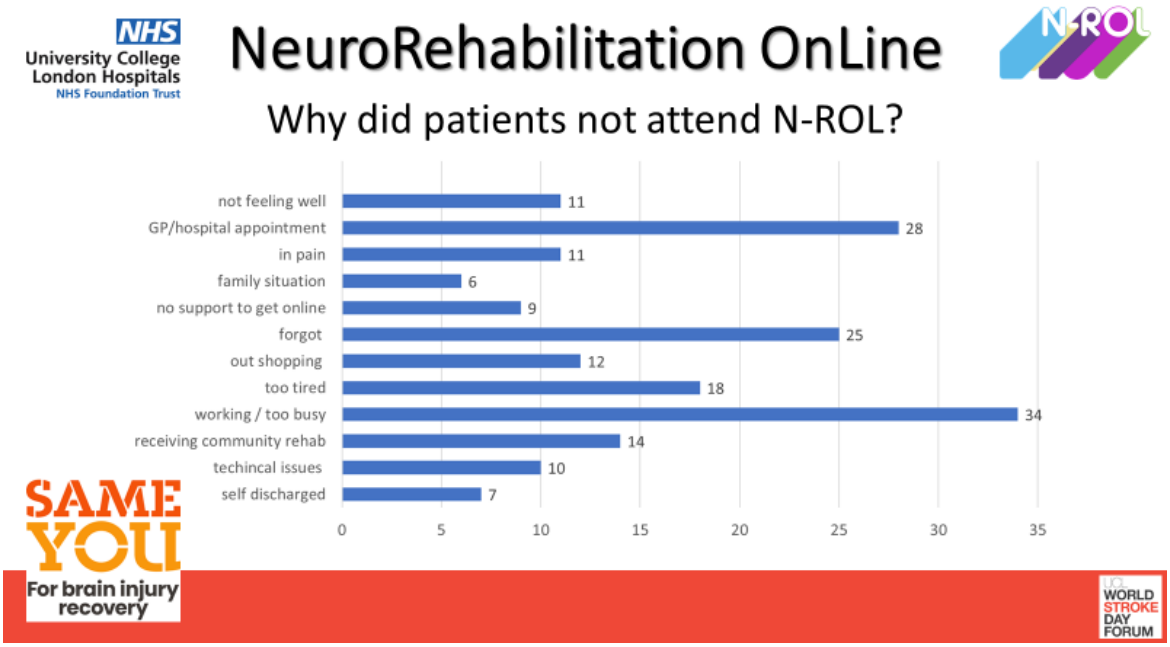
A **quarter** of **people did not meet** our **criteria**. We set our criteria as being **people within six months** of **discharge** from **hospital post-stroke** or **brain injury**.

Another **large proportion** of people **declined** as they did not want to **take part** in **online services** or **online platforms**.

Another **large proportion** of people **did not want** to take part in **group therapy** or **group rehabilitation**.

And another **significant proportion** felt they'd **already improved significantly** and therefore no longer required our service.

This next **slide** shows why some people were **not able to attend** some sessions.



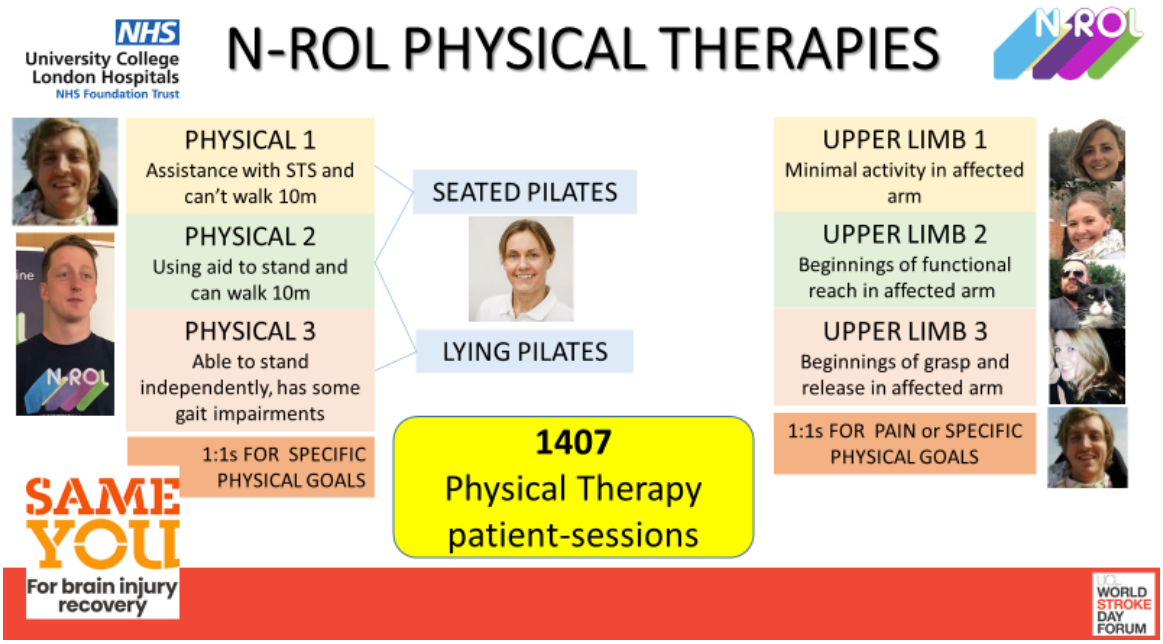
So, some people were **not able to attend** due to GP eappointments or they had they were **busy** with other work commitments.

And another **significant portion** where people would have forgot. Which brings us to an important point of our **N-ROL service development** where we were able to get **volunteers** into the service to **ring patients** to **remind** them of sessions.

This also helped us develop our **accessibility** of our **timetable structure**, to make sure our **timetables** had **easy to use embedded links** but also made sure that our sessions were fitted into points of the day which were most **convenient** to our participants.

I think that this is a **really important valuable** component for anyone setting up a service like this. To have **people ringing regularly** to help support people with this component.

So, I was in charge of the **physical component** of **N-ROL** which this slide (below) sets out, and the **physical component** was **stratified** into **three levels** of **ability:** Physical one, two, and three, with three being the highest level of ability.



And the **sessions** were roughly **30 minutes to 45 minutes** where we worked on **strength**, **endurance** and **functional task practice** in multiple anatomical planes.

Also working on **balance** to try to help people **reduce** their **falls risk**. But generally feeling like people felt like they were getting stronger in multiple different directions.

And finally working on **cardiovascular fitness** which is also another really **important component** of **recovery post stroke and post brain injury**.

We were lucky to have the support of **Kate Bull** who also provided **seated pilates** and **lying pilates** according to different levels of ability, to work on **core strength** and also to work on **range of movements**.

And in addition, if people had **upper limb impairments**, they were then **stratified** to **three different levels of ability** and they were then **supported** by the **specialists** from the **Queen Square Upper Limb Programme**, who worked on **functional task practice** and lots of **education** about how to **self-manage upper limb rehabilitation** at home.

If there was a **barrier** to any components of the **physical rehabilitation** such as **pain**, or things like **getting on** and **off the floor**, I would often do **one-to-one sessions** so that we **reduce** that **barrier** so people could participate fully.

Generally, we found that we had **1,407 physical therapy patient sessions** in total that we provided.

What we found is we were able to provide **three sessions per week** so **two** of the either **physical 1, 2 or 3**, in addition to **pilates**. And if somebody had an **upper limb impairment** we were able to provide **four**.

So, we were giving really **good amounts** of **physical dosage** to people at home in addition to maybe what they were getting in the community or with their private therapist, or if they were not getting anything a nice dosage for them to work on their physical goals.

Talk Transcript – Dr Catherine Doogan

Hello I'm **Dr Catherine Doogan** and I'm here to talk to you today at World Stroke Day about the talking **therapies** that were involved in the **NeuroRehab OnLine** service that we created with the funding from **SameYou**.

As Ben will have mentioned we **screened** all of **patients** and they received **outcome measures** and were talked to about the different types of **group interventions** that they were referred for.

After this **everyone** was **invited** to **meet** the **team**.

So, that involved **meeting myself** and **Ben**, the **neurophysio**, and a **neurologist**, usually **Alex Leff** or **Nick Ward**.

Then everybody was invited to four sessions of **'Me, my stroke and us'**, our **brain injury education** group. And everybody could ask any **question** that they had about their **stroke** or **brain injury**, about **worries** they had, **symptoms**, **causes of stroke**, and lots of **different** types of **questions**, and sometimes really **unhelpful health beliefs** that people really worried about.

Then in the **talking therapies** people either received some **emotional support groups** with me (and we used **ACT** therapy, so **acceptance and commitment therapy**) or **cognitive rehab** that myself and an occupational therapist, Kate Kelly, did.

And also, we offered a **caring** café. So we realized that whilst the stroke happens in one person's brain, actually, the **impact** of the **stroke** can **influence** many many **different people**. So, family members living at home and other friends and support networks. Of course, during **Covid** this was really **difficult** for people who couldn't access those **support networks** in the same way.

Fatigue is a huge **symptom** after **stroke**, as I'm sure you know, and so occupational therapists ran some **fatigue management groups**.

And **communication**; we know that **aphasia** is a really difficult thing for people after stroke to live with it has **huge psychological consequences**. And so, we had **three different types** of **communication groups**: **aphasia**, **dysarthria** and **cognitive communication** groups.

This was predominantly a **group intervention** but, of course, some people needed more **one-to-one** and we also provided this at **N-ROL**.

So, there may be a reason to talk to the **medic** about some of the more medical **side** of things and so they would have a **one-to-one** with a **doctor**.

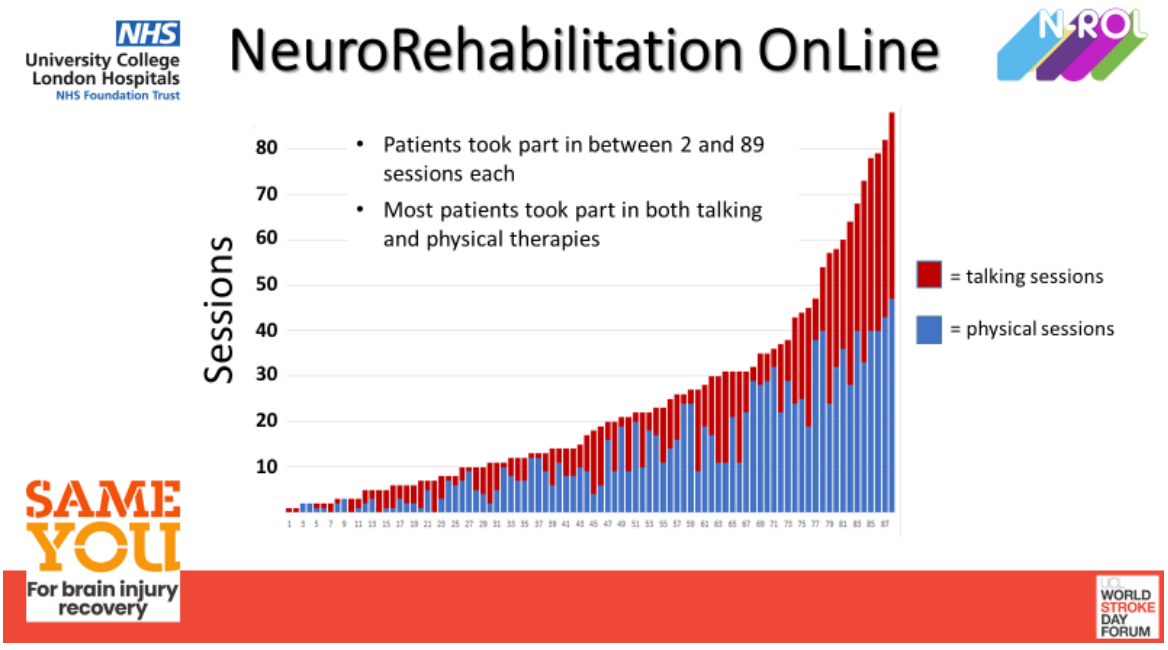
Or perhaps, as Ben will already have said, if some **pain** or any **issue physically** came up, he would give them a **one-to-one**.

And similarly, with me if there were any **risk** or **mood issues** then I would see the people on a **one-to-one** basis or with their **family members**.

In total we had **925 attendances** in **talking therapy**.

But no one size fits all. So, what we do know is that **stroke** can **impact** on lots of **different parts** of people's **lives**, both **physical** and **non-physical**.

And this **graph** shows our **patients** along the **bottom**, so every **bar relates** to a **person**, and the **difference** of the **mix** of **physical** and **talking therapies** that they got, and as you'll see **nearly everybody** got some of **both**.



And we think that **represents** the **complex nature** of **stroke** and also how our **intervention** at **N-ROL** dealt with and tried to **address** all the **different aspects** of **stroke**.

Okay and then just more generally **N-ROL reflections**.

So a **NeuroRehab OnLine** service for **stroke** and **brain injury patients** is possible. It is **possible** to do this **online** I think we found.

And people had **access** to **numerous appointments** with a **consultant neurologist**.

We provided **psychoeducation** through **patients sharing** their **own stories** and **listening** to others.

And this really **facilitated insight** and **awareness** and they reported **feeling less alone**. And it was experienced as **normalizing**: “Oh I feel that too. I experienced that as well”. And some people had **never** even **met anyone else** that has had a **stroke**, so the **idea** of doing it in a **group**, actually, they really really **liked**.

It provided **structure** and **routine** through the **weekly timetables** in an **uncertain**, **highly anxious**, and **isolating** time.

So, **every week** Pedro would send out **timetables** to all the **patients** and that really **set up** a nice kind of **structure** that people would be able to **adhere** to, and give them a **sense of routine** and **purpose** for the day.

As I've said, we did this through **systemic working**, so husbands, wives, sons and daughters attended some of the interventions with their loved ones.

Carers working from home, as I've mentioned, could log in **once a week** for their **weekly therapeutic hour**.

And these **sessions** you know people really **shared painful experiences**; **laughed** and **cried** with each other, and often, as I've said, during their lunch break.

And really the **feedback** from the **patients** who came to us at **N-ROL**, they and their **carers** are really **grateful**. They really want to **raise money** or **awareness** for others.

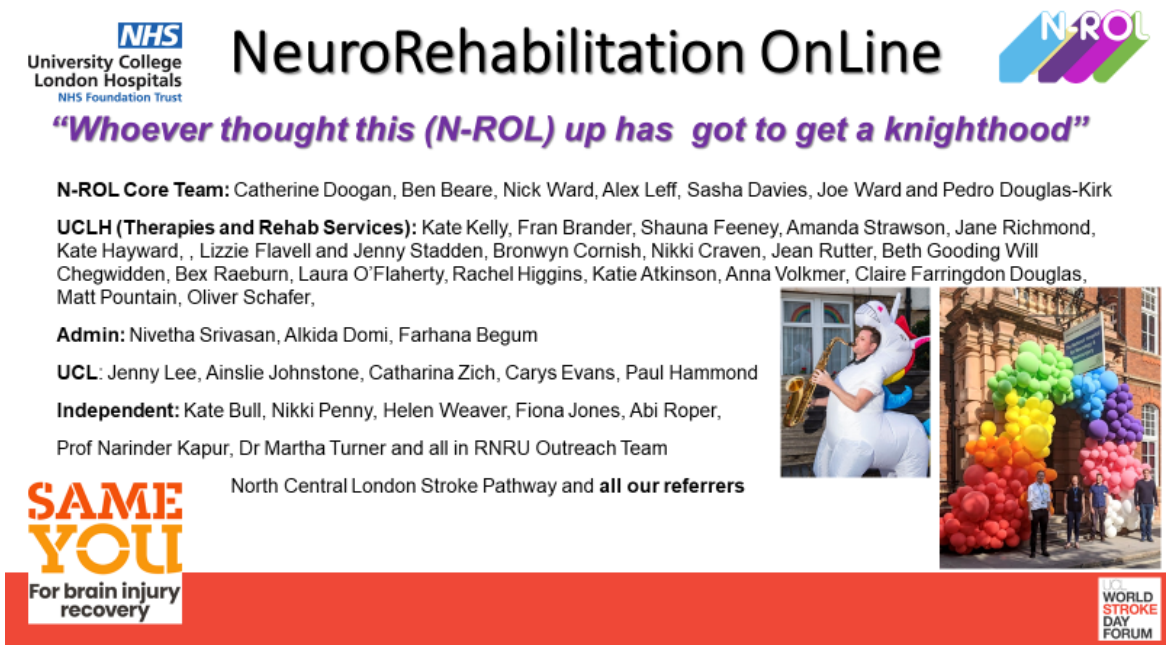
And they've reported **feeling held** and **contained** in, for all of us, what has been an **unprecedented time** and a very **anxious time** for many of us.

And they also wanted to **remain in touch** with each other so with consent we've shared their emails with each other and they **continue** to **offer** each other **peer support**.

So, what **N-ROL** has actually been able to do is to create a **fully online community rehab service**, where no one asked or cared about anybody's postcode, and no one got more or less rehab as a result.

But there are many people that have **contributed** to this **process**. And we didn't know how to thank them, so one of our patients thought up that “Whoever thought this N-ROL up has got to get a Knighthood.”

So, the following on this slide is all the people that have helped us to set up and to **execute N-ROL** and we can't **thank them** enough.



We also have to give a big shout out to **SameYou** who provided and actually enabled this project to get going.

A special thank you in pink at the bottom is **Pedro Douglass-Kirk**, who we couldn't have run this project without, and he provided a much **technical** and **psychological support** to all the **patients** he rang every day, to remind them and encourage them to come to our groups so thanks Pedro.

And also to Nick Ward and Alex Leff and my colleague Ben Beare. It's been an absolute pleasure running this service and we hope that the outcomes and what we find through all our outcome measures that we've collected will show that it's **effective** and that perhaps **more people** will get **services** like this in their **own homes**.

Thanks very much

Talk Transcript – SameYou

Emilia Clarke: **SameYou** asked for your help during **COVID**. Your **fundraising** and **generosity** has enabled the **pilot programme N-ROL**, **virtual neurorehabilitation clinics** led by **UCL** for **stroke** and **brain injury** patients.

Prof Nick Ward: **N-ROL** is a form of **telerehabilitation**. So we have one or two therapists who are able to communicate with probably between five and maybe 20 patients in one session.

Physiotherapist: *"Now we need five down, five up. Down one, two, three, four, five. Up five…"*

Prof Alex Leff: People **join** into the group **remotely**, using a technology that a lot of people will be familiar with, and they speak in **real time** with a **therapist** or group of therapists who talk them through that particular session.

Prof Nick Ward: **UCL** is already doing some work with **SameYou** in the field of **neurorehabilitation** and **neurorecovery**. And when the **COVID-19 pandemic** came along, they were very keen to do something **innovative** and **useful**.

The thing that we identified was that it's likely that patients are going to get **discharged** from the hospital **much sooner** than normal. And we'd have a **large population** of **patients** at **home** who are **not receiving** the **neurorehabilitation** that they need.

And so it was really about trying to come up with **innovative ways** that we can get that kind of **therapy** and that kind of **support** into people's own **homes**.

Prof Alex Leff: We've got **physiotherapists**, **clinical psychologists**, **speech and language therapists**, and **occupational therapists**, as well as **clinicians**.

Prof Nick Ward: There are things that you can do with **N-ROL** that you can't do with standard approaches. Simply, we'll be able to **reach more people**.

Ben Beare: The great thing about the **group interactions** is that people who are **socially isolated** on their own are able to get that **peer support**. And also we find that probably their **sustained effort** is maybe **higher** than they would be able to achieve at home because there's more people around them **encouraging** them.

Dr Catherine Doogan: People are in their own homes, getting rehab. And they've told us that this is really great. So I think there's something about this in the future that this may be a different way of **meeting people's needs** within their **own homes**. And I think that's really exciting.

Prof Nick Ward: We just want to **thank** all the people who have **supported** the **SameYou COVID-19** campaign. With your help, we've been able to get the project up and running and really begin to make a **difference** to **people's lives**. So, from all of us, thank you so much.

Emilia Clarke: There's still more to do. Please **support** us and help us **continue** our **work**.

Glossary

Aphasia: Aphasia is a communication disorder that affects expression and/or understanding of speech and language.

Dysarthria: difficulty speaking.

NeuroRehab OnLine @ Queen Square
https://www.ucl.ac.uk/ion/research/departments/clinical-and-movement-neurosciences/people/ward-lab/neurorehab-online-queen

Same You
https://www.sameyou.org/