revive MS
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REVIVE MS CONNECT – REPORT
NEUROLOGICAL CARE AND SUPPORT FRAMEWORK 2020-2025

CONTEXT

Revive MS Connect is a Scotland-wide digital health programme aimed at providing equal access to services and support for people with incurable, disabling, Multiple Sclerosis. The Programme provides, for the first time, a new digital pathway into multi-disciplinary, MS-specialist, services, targeting those with MS who are unsupported or under-served, nationwide.

Preceded by three years of planning and evaluation, the Programme was piloted in 2018/19. This confirmed the feasibility of delivering MS services using digital platforms and clearly evidenced the efficacy of a single digital pathway in terms of improved health outcomes for people with MS, reducing daily pain and suffering, increasing self-management capability, reducing isolation/improving connectedness, and preventing both health decline and recourse to primary or emergency care.

Based on the results of the pilot, and with the support of the Scottish Government – through *Neurological Care and Support: A Framework for Action 2020-2025* – and a small number of additional funding partners, Revive MS Support began the national (phased) roll-out of *Revive MS Connect* in 2021.

ACTIVITIES

Revive MS Connect supported **467 unique individuals with Multiple Sclerosis** over the 18-month period from June 2021 to December 2022, delivering a total of **1611 clinical and non-clinical interventions**.[1] This included:

INTERVENTION	**No.**
MS Specialist Nurse Assessments/Reviews	150
Counselling/Mental Health Support	442
Physiotherapy Consultations	80
Speech and Language Therapy	45
Welfare & Benefits Support	687

Revive MS Support's original target was to reach at least 2 additional people with MS, per week, using digital platforms, across each of Scotland's 14 regional health-board areas – this was based on our awareness of the significant unmet need for support, at the local level, nationwide, and on our cultivation of the largest MS-specific digital referral network ever seen in Scotland.

In practice, the number of beneficiaries was impacted by several factors, including initial limitations on network expansion and pandemic-related factors out-with our control (as explained in previous evaluations). This included: an unexpected delay in recruiting a clinically experienced National Coordinator for the Programme, which delayed the implementation of the Programme by some months (although network cultivation efforts continued, at some level, across the whole of 2021, and saw a significant acceleration from November 2021 and throughout the whole of 2022); and overarching COVID-related challenges (particularly travel and communication restrictions). It should also be noted that we encountered some reticence, latterly, towards the use of digital services, based on the level of social isolation and service restriction experienced by people with MS during lockdown (evidenced in multiple peer-reviewed studies e.g., Yeni et al., 2022, and in multiple surveys e.g., Neurological Alliance, *Restarting Services*).

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[1] A final update on the interim figures provided to the Scottish Government in early December 2022, following the completion of a full data analysis.

BENEFICIARY PROFILE

A breakdown of the profile of those reached through the Programme is as follows:

PROFILE	%
Male/Female	44/56
Health Board Area - **Greater Glasgow & Clyde** (Covering an extensive area, including e.g., Lochgilphead, Milton of Campsie, Inverkip etc.)	76
- **8 additional health-board regions** Lanarkshire Ayrshire & Arran Dumfries & Galloway Fife Forth Valley Grampian Tayside Lothian (Including Aberdeen, Cupar, Kirkmuirhill, Twechar, Stranraer, Elgin, Girvan, Bo'ness, Forth, Whitburn, Callander and much more)	24
Referral Source	
- Self-referral	20
- GP	4
- MS Nurse	65
- Neurologist	1
- 3rd Sector Partner	10

This data clearly demonstrates that Revive MS Connect had a *national* impact over the grant period, reaching unsupported people with MS from across Scotland with debilitating MS symptoms.

The following qualitative case-studies (with names and other identifiers changed) illustrate the physical, mental, and social health outcomes of the Programme for those affected.

REPRESENTATIVE CASE STUDIES

70% of people with MS are affected by debilitating continence issues at some point in their lives, with e.g., urinary incontinence, carrying a five-fold increased risk of hospitalisation, and an elevated risk of early death. **A 34-year-old man who has Relapsing MS** and lives in a rural area in the Scottish central belt, developed serious, MS-related, urinary incontinence, in 2020. This affected his mental health and confidence, curtailed his social life (weekly pub visits and football with friends), and prevented him from caring for his elderly father. Referred for urology assessment by his GP, he was placed on a 2-year waiting list and, in the interim, was hospitalised on multiple occasions with urinary tract infections. Prompted by his sister, who was concerned for his safety and well-being and who had heard about Revive through word-of-mouth, he contacted us through our digital self-referral pathway. Assessed within two weeks of contacting us by our MS Specialist Nurse, he was signposted to our continence clinic. He was subsequently assessed by our Continence Specialist Nurse, using the Coloplast Bowel and Bladder Health Check (20-Item Scale), and received an ultrasound bladder scan. Based on the results, he began intermittent self-catheterisation, immediately improving his quality of life. He has since regained his confidence and fully resumed his social life and caring responsibilities.

A 55-year-old man from Fife, who has Progressive Multiple Sclerosis and is unable to walk, was referred to us by a hospital doctor shortly after his discharge following an attempted suicide – 40% of the 718 participants in the MS Trust's 2022 UK-wide survey had suicidal ideation (*Life Changing*, April 2022). Suffering from debilitating spasms – one of the hidden disabilities that affects no less than 50% of people with MS in Scotland (see *Future MS*) – which had not responded to medical treatment, he was completely housebound, awaiting wheelchair accessible housing. With no relatives around, his only daily contact was with council care workers who come in four times a day for 15 minutes to meet his most basic needs. He was struggling with the indignity of this and feeling very isolated. Following an initial MS Nurse assessment, he was signposted to our Counselling service. Weekly Zoom sessions have since given him the opportunity to talk about whatever is on his mind. We also put in place a co-produced safety plan, giving him options if he is feeling suicidal again, and have signposted him to respite care so that he is able to go away for a supported short break. Although his situation remains very difficult, his outlook has improved and his sessions have recently reduced to every fortnight – our support has helped to stabilise his mental health and prevent recourse to emergency and primary care, whilst he awaits an improvement in his living conditions.

A 38-year-old woman from Argyll & Bute, was also signposted into our Counselling service by our MS Nurse. With a management-level job, she was struggling to cope mentally, emotionally, and physically, and at imminent risk of losing her job, due to MS-related fatigue and cognitive impairment (the main reasons for employment reduction amongst people with MS); she was also suffering from PTSD related to an incident some years ago. Our Lead Counsellor worked with her, using evidence-based trauma-informed CBT, on a weekly basis, to explore her feelings of distress and reduce their impact on her day-to-day life. She has since developed a new resilience, feels better able to manage her work responsibilities and, following additional MS Specialist Nursing and other support through Revive, has improved the self-management of her MS symptoms.

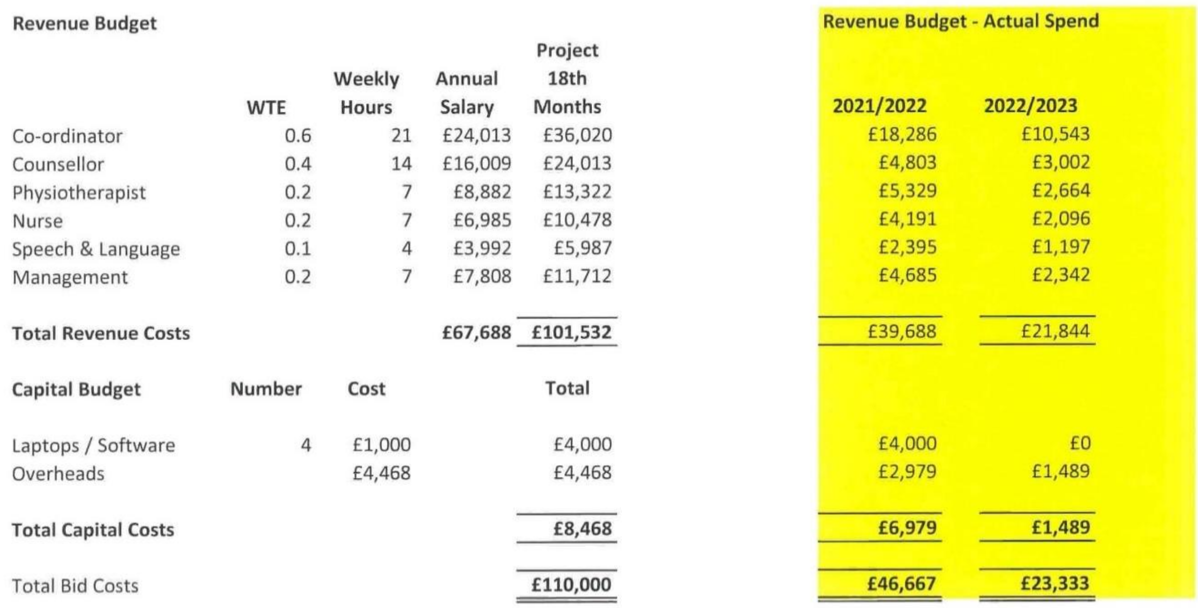
Amongst the 126 people, like the two examples above, who benefitted from counselling and mental health support through *Revive MS Connect* over the past 18 months, *depression scores fell by 52% on average*, and *anxiety scores by 35%* (measured at 2 data points – baseline and after an average of 7 sessions – using the PHQ9 and GAD7 scales).

Our Welfare and Benefits provision has also been widely accessed using *Connect*, more than we originally projected. Examples of positive outcomes include a **44-year-old woman from Aberdeenshire** and with a young family, she had been coping with a cascade of MS symptoms – ranging from muscle spasms, nerve pain and balance issues, to fatigue, depression, and anxiety – for 7 years, prior to formal diagnosis in 2020. Other than regular hospital visits for supervised treatment with strong disease modifying drugs (which can cause temporary weakness/debilitation), she was totally unsupported. She had also become isolated, avoiding people outside of her family due to communication difficulties: "I muddle up words, forget what I am saying or say something stupid, mumble or can't keep up with the conversation due to processing speed issues and just stop speaking as I'm mentally tired". As a result, she was no longer able to sustain employment. She turned to us for the first time, in desperation, in August 2022, subsequently (with the guidance and advocacy of our Welfare and Benefits Officer), securing £7,956 per annum in Adult Disability Payment.

These case-studies demonstrate that Revive MS Connect has reached some of the most vulnerable, isolated, and at-risk people living with MS, across Scotland, over the past 18 months, in many cases addressing immediate, critical needs, stabilising their position, and reducing their risk of further, serious, mental, physical and social health deterioration.

BUDGET UPDATE

Details of our expenditure of the funds received for *Revive MS Connect* from the Scottish Government, through the Neurological Care and Support Framework, are as follows:



Revenue Budget					**Revenue Budget - Actual Spend**	
	WTE	**Weekly Hours**	**Annual Salary**	**Project 18th Months**	**2021/2022**	**2022/2023**
Co-ordinator	0.6	21	£24,013	£36,020	£18,286	£10,543
Counsellor	0.4	14	£16,009	£24,013	£4,803	£3,002
Physiotherapist	0.2	7	£8,882	£13,322	£5,329	£2,664
Nurse	0.2	7	£6,985	£10,478	£4,191	£2,096
Speech & Language	0.1	4	£3,992	£5,987	£2,395	£1,197
Management	0.2	7	£7,808	£11,712	£4,685	£2,342
Total Revenue Costs			**£67,688**	**£101,532**	£39,688	£21,844
Capital Budget	**Number**	**Cost**		**Total**		
Laptops / Software	4	£1,000		£4,000	£4,000	£0
Overheads		£4,468		£4,468	£2,979	£1,489
Total Capital Costs				**£8,468**	**£6,979**	**£1,489**
Total Bid Costs				**£110,000**	**£46,667**	**£23,333**

EVALUATION & SUMMARY OF OUTCOMES

From the outset of the Programme, we have collected objective quantitative and qualitative data (referenced above in the case studies), underpinned by independently validated outcome measures relative to each intervention. Based on the available data, the Programme has achieved the following overarching and specific outcomes:

- Establishment and operation of a new, 36-member, national referral network of MS-associated clinicians and non-clinical partners/stakeholders.
- Launch/operation of a new digital support pathway open to anyone with MS who is unsupported, nationwide.
- Increased connectedness for those affected, Scotland-wide.
- Reduced isolation, loneliness, and hopelessness.
- Reduced suffering and increased self-management capability.
- Improved mental health and resilience.
- Improved physical health and mobility.
- Improved financial stability.
- Increased independence.

The Programme has also:

- Facilitated early intervention/prevention for people at high risk of further mental, physical and social health decline.
- Reduced recourse to primary and emergency care for people with manageable symptoms.
- Supported the rehabilitation and reintegration of people shielding due to COVID and assisted recovery/symptom management associated with long-COVID.
- Provided external advocacy for people unable to represent their own interests.
- Signposted those affected to critical external services based on their support needs, including both statutory and 3rd Sector provision.

CHALLENGES

As noted above, we encountered specific challenges that partially restricted the growth of the Programme over the grant period. However, these were mainly transitory difficulties that limited the number of people reached by the Programme and the growth of the referral network, with only *minimal implications* for the future growth and potential of the Programme. Additional factors that we encountered to those outlined above included:

- Limited but notable reticence towards digital services (briefly referenced above), based on lockdown/shielding experience – this was also encountered by our statutory and third sector partners.
- Delayed roll-out of our social media and advertising schedule due to the integration of a new Communications and Digital Marketing Team.
- Limited GP engagement – although we are currently exploring promotion through our podcast, and through GP leafleting, to increase referrals, we made less progress on GP direct referrals than we had hoped, with significant additional groundwork required.

FUTURE PLANS

Having completed a full evaluation of the roll-out of *Revive MS Connect* and carefully reviewed the opinions and experiences of our clients (through post-intervention measures and a recent major client survey), we intend to:

- Further embed *Revive MS Connect* into our core service provision – this reflects the impact of the Programme that we have seen on the lives of so many people with MS who have no other support and are, most often, outside of the health-care system.
- Continue to develop our successful partnership with the MS Nurse network nationwide – this prompted most of the referrals into the Programme over the past 18 months.
- Extend our referral partnership with the MS Society's national *Wellbeing Hub*.
- Delivering dedicated group provision, including physiotherapy, counselling, mindfulness, and other highly-valued services over the *Connect* platform – this will significantly increase the number of people reached through the Programme.
- As noted above, fully develop a GP referral pathway – based on the experience of 3rd sector partners engaged in other clinical areas (Stroke, MND, Parkinsons).
- Extend face-to-face and digital referral network development activities.
- Further engage in efforts to develop national standards for MS services, nationwide.

In terms of sustainability, the main sources of funding that we expect to secure in support of the further development of the Programme, over the coming years, include:

- The pharmaceutical industry – we are in advanced discussions with several pharmaceutical companies.
- Additional grant funders, both national and local.
- Limited regional NHS Health-Board funding.

We have already secured limited additional funding that will enable us to continue to develop aspects of the Programme in the short term. Combined with recent strengthening of our marketing and communications capability, reinforcing our brand identity and social media presence, we expect to see a significant increase in awareness of the Programme, to engage new partners and to be well-positioned to secure additional funding, moving forward.

The further extension of nationwide digital access, through Revive MS Connect, to MS-specialist services, without recent constraints, will have a significant impact on the lives of the most excluded people with MS, Scotland-wide, with implications for multiple Scottish Government policy priorities.

ENDS