



Self-management Support



REPORT ON THE IMPACT OF THE HSE LIVING WELL PROGRAMME

Supporting people with chronic health conditions to develop skills and confidence to self-manage



Delivery of the Living Well Programme was funded by the Government of Ireland's Sláintecare Integration Fund 2019, under Grant Agreement numbers 38, 78, 185, 219, 413, 418 to support the delivery of services, which focus on prevention, community care and integration of care across all health and social care settings.



Rialtas na hÉireann
Government of Ireland



“ I learned so much about myself and living with my illness. Previously I would let my illness and symptoms consume me and it would greatly affect my mental state. I never realised there was a different way of thinking and managing my life. It never crossed my mind before that I could have an impact on my own health. ”

(Living Well Programme participant, Co. Donegal, 2020)

TABLE OF CONTENTS:

Acknowledgements	4
Foreword	5
Introduction	6
Background	9
Context.....	10
Testing the delivery and effectiveness of the Living Well Programme.....	11
Discussion of key findings.....	14
Conclusions and considerations.....	27
Glossary of acronyms and terms	28
References.....	29
Appendices	30

This report has been compiled by the National HSE Self-Management Support Coordinator Group (including previous members):

Maeve McKeon, Self-management Support Coordinator (previous), Community Healthcare Cavan Donegal Leitrim Monaghan Sligo (CHO 1)

Claire Hennigan, Self-management Support Coordinator, Community Healthcare Cavan Donegal Leitrim Monaghan Sligo (CHO 1)

Ailish Houlihan, Self-management Support Coordinator, Community Healthcare West (CHO 2)

Ruth Reidy, Self-management Support Coordinator, Mid-West Community Healthcare (CHO 3)

Maeve Carmody, Self-management Support Coordinator, Cork-Kerry Community Healthcare (CHO 4)

Rosaleen Mac Uistin, Self-management Support Coordinator, South East Community Healthcare (CHO 5)

Mary Gowing, Self-management Support Coordinator, Community Healthcare East (CHO 6)

Mary Rose Cunningham, Self-management Support Coordinator, Dublin South, Kildare & West Wicklow Community Healthcare (CHO 7)

Ger Walsh, Self-management Support Coordinator, Midlands, Louth, Meath, Community Healthcare Organisation (CHO 8)

Caroline Peppard, Self-management Support Coordinator, Community Healthcare Organisation Dublin North City & County (CHO 9)

Kate O Connor, Self-management Support Coordinator (previous), South East Community Healthcare (CHO 5)

Sinead Power, Self-management Support Coordinator (previous), Midlands, Louth, Meath, Community Healthcare Organisation (CHO 8)

Ger Cully, Self-management Support Coordinator (previous), Dublin South, Kildare & West Wicklow Community Healthcare (CHO 7)

ACKNOWLEDGEMENTS

Thank you to Professor David Hevey, **Principal Investigator**, TCD Research Project, Trinity College Dublin (TCD).

Thanks also to the members of the **Research Advisory Group (RAG)** who supported the TCD research:

Dr. Olga Cleary, Chair of RAG, HSE Research Lead for Health & Wellbeing, South East Community Healthcare

Maeve McKeon, HSE Self-Management Support Coordinator, CHO 1

Caroline Peppard, HSE Self-Management Support Coordinator, CHO 9

Dr. Jenny Wilson O' Raghallaigh, Principal Clinical Psychologist Beaumont Hospital; Living Well Master Trainer and Quality Support Mentor; Stakeholder Advisor

Dr. David Evans, Research and Data Officer, National Social Inclusion Office; Research Advisor

Laura Mac Neill, Living Well Programme Peer Leader (Irish Society for Crohn's and Colitis); Stakeholder Advisor

Thanks to the **Your Voice Matters** team, Barbara Riddell and Mairead Fennessy, who led on the report of the South East Community Healthcare Participants' Experience of the Living Well Programme.

Our thanks and gratitude also goes to

1. Self-management Support National Advisory Group (Interim)
2. Derval Howley, Head of Service Health and Wellbeing South East Community Healthcare (SECH) and National H&W representative for SMS
3. Sláintecare
4. Living Well Programme Leaders, Quality Support Mentors and Master Trainers who took part in the process evaluation
5. Service-users who completed the surveys.

FOREWORD

A Message from Derval Howley

Head of Service Health & Wellbeing, South East Community Healthcare
Head of Service National Representative for Self-management Support

I am delighted to welcome the Report on the Impact of the HSE's Living Well Programme.

In 2019, the Self-management Support programme in six Community Healthcare Organisations applied for and were awarded funding under Sláintecare to deliver the Living Well Programme across their respective regions. This report provides an easy to read overview of the programme itself and key data on those that attended the programme.

It highlights the many positive impacts that this programme had on the participants. The impacts include significant increases in quality of life, exercise levels, confidence to self-manage their own health and to engage with other e-health interventions. They also include significant decreases in unscheduled GP attendance, levels of reported depression, and how their health conditions impacted both their social activities and employment role.

Quality of life was measured at 3 intervals; in advance of commencing the programme, on completion, and at 6 months post programme. It was fantastic to see that the positive impacts were maintained following completion of the programme.

The Self-management Support Coordinators themselves faced many challenges as they set about delivering the programme, not least the COVID-19 pandemic. As the programme was aimed at people who had long-term chronic conditions, it was not possible to continue to bring people together face to face. Innovation prevailed and the programme was adapted for online delivery.

This report documents the learnings and outcomes from the implementation period. It also highlights the added benefits of the programme including the peer support that developed amongst participants.

This document allows us to describe the programme, the evidence of the positive impact it can and does have on the lives of those that participate, and our learnings as we set about delivering it across six community healthcare organisations.

The Living Well Programme continues to be delivered both online and in person. For further information, please visit www.hse.ie/LivingWell

INTRODUCTION

The Living Well Programme is the name given to the Stanford model Chronic Disease Self-management Programme (CDSMP)* delivered by the HSE.

It is a structured, evidence-based, group programme, which supports participants to develop self-management skills, thereby improving their health outcomes and quality of life. The programme is peer-led and delivered over six workshops.

Traditionally delivered as a face-to-face programme, the Living Well Programme moved to an online delivery model during the COVID-19 pandemic. Post pandemic, a blended model of programme delivery has emerged, offering both online and in-person programmes.

Supporting self-management is an essential element in chronic disease management. The Living Well Programme aligns with the Model of Care for the Integrated Prevention and Management of Chronic Disease by providing an evidence-based programme, which empowers people to manage their chronic health conditions and provides them with the support to develop the necessary skills to do so. With a focus on community-led support to stay well and manage their health conditions

as independently as possible, the Living Well Programme also meets many of the goals of Sláintecare.

The Living Well Programme was supported by the Sláintecare Integration Fund (2019) across six Community Healthcare Organisations (CHOs) from January 2020 to December 2021. This report communicates the achievements of the programme during this implementation period as reported by an independent evaluation led by Professor David Hevey, Trinity College Dublin. Implementation was led by the HSE Self-management Support Coordinators (Appendix 1). The outcomes demonstrate the value of the Living Well Programme in supporting participants to become effective self-managers and active partners in their healthcare, thereby improving their health outcomes. Furthermore, the outcomes underline the potential of the Living Well Programme to be part of the successful 'shift left' as envisaged by Sláintecare.



* <https://selfmanagementresource.com/>

PROJECT OVERVIEW JAN 2020 TO DEC 2021



KEY FINDINGS AT A GLANCE



SIGNIFICANT INCREASES IN PARTICIPANTS'

92%
of respondents completed the programme (defined as attendance at 4 or more of the 6 workshops)

94%
of participants were satisfied with the programme


The peer-support aspect was highly valued by participants and peer leaders

- Quality of life
- Exercise levels
- Confidence to self-manage health
- Confidence to engage with other e-health interventions
- Perceptions of supports available to manage health



SIGNIFICANT DECREASES IN PARTICIPANTS'

- Levels of depression
- Illness interference with social role
- Illness interference with employment role
- Unscheduled GP attendance


Key positive outcomes were sustained at 6mths post programme completion, indicating that programme benefits are maintained over time.

35%
decrease in unscheduled GP attendance



Due to increased confidence and skills of the participants to self-manage.



BACKGROUND

Supporting self-management is a critical element of our journey toward building a more sustainable health service. The *National Framework for the Integrated Prevention and Management of Chronic Disease* (HSE, 2020) describes self-management support as a foundational component in delivering end-to-end care for people living with chronic conditions. A key focus of this framework is the development and integration of services and supports which will enable people to self-manage and live well with their health conditions. The National HSE Self-management Support Framework (HSE, 2017) recommended the provision of 'generic chronic disease self-management education programmes as part of a range of available self-management supports'. The evidence-based Stanford model generic CDSMP is one such programme.

This programme was developed by a team of researchers at Stanford University in the United States (US). Governance and licensing of the programme is now managed by the original team through the Self Management Resource Centre (SMRC) in the US (<https://selfmanagementresource.com>). It is a structured, six-week, peer-led programme for adults with chronic health conditions. Workshops are delivered once per week for six weeks. Each workshop lasts two and a half hours, and is delivered by trained Peer Leaders, who are themselves managing a chronic health condition. This programme seeks to empower patients with the skills and confidence to better manage their chronic conditions and engage as active partners in their healthcare. This results in informed and empowered service-users, who are enabled to optimise their health and quality of life.

The content of the workshops is generic in focus; therefore, it is suitable for people living with any chronic condition e.g. Chronic Obstructive Pulmonary Disease (COPD), asthma, diabetes, heart disease, stroke, multiple sclerosis, arthritis etc. Participants are supported to develop a 'Toolkit' of skills to enable self-management.

Toolkit for self-managing your chronic condition

- Goal setting
- Action planning
- Problem solving
- Decision making
- Physical activity
- Healthy eating
- Sleep
- Pain management
- Medication management
- Understanding emotions
- Better breathing
- Using your mind to manage symptoms
- Communication
- Working with your healthcare team
- Making informed treatment decisions



CONTEXT

i. CDSMP delivery in the HSE: The Living Well Programme

The Stanford model CDSMP had been delivered sporadically in some parts of Ireland since 2005, through local HSE services or through the voluntary sector. The National HSE Self-management Support (SMS) Coordinators Team sought to address this inequitable access, and the Slaintecare Integration Fund (2019) provided an avenue through which to do so.

Recognising the potential for the CDSMP to deliver on key objectives of the Slaintecare vision, SMS Coordinators in six Community Healthcare Organisations (CHOs) successfully submitted for Slaintecare Integration Funding (SIF), and worked together to deliver a more streamlined CDSMP across six CHOs in the HSE.

The SMS Coordinators from all nine CHOs established a National Working Group to oversee the roll out of the programme in the HSE, under the brand name *'Living Well – A Programme for Adults with Long-term Health Conditions'* (known in short as the Living Well Programme). They agreed standard operating procedures, created new branding and promotional materials, and developed a webpage on the HSE platform. Various means including social media were utilised to promote the programme and the working group engaged the support of HSELive as a centralised point of contact for the programme.

ii. Emergence of the online Living Well Programme in response to the COVID-19 Pandemic

With the onset of the COVID-19 pandemic in March 2020, it became apparent that people living with chronic health conditions were particularly vulnerable. The Living Well Programme teams recognised the need to balance the protection of this vulnerable cohort with their need for self-management support, while contending with widespread lockdowns, cocooning and changes to their usual healthcare supports.

The Programme Leads responded by designing an online model of the programme, in collaboration with other CDSMP partners in Ireland.

By pivoting to online delivery, the Living Well Programme demonstrated its responsiveness to patient need - supporting and empowering individuals to increase their self-management skills and optimise their health, in order to stay well and avoid hospital admission during what was an unprecedented and protracted challenge for healthcare services.

TESTING THE DELIVERY AND EFFECTIVENESS OF THE LIVING WELL PROGRAMME

i. Collaborative research project:

Testing the effectiveness of the Living Well Programme was a key objective of the SMS Programme during the Sláintecare Integration Fund implementation phase. While a large body of evidence demonstrates the effectiveness of in-person CDSMPs in improving a range of participant outcomes including quality of life, self-efficacy, health behaviours, anxiety and depression, the question remained if an online CDSMP delivery model could confer the same benefits for people living with chronic health conditions. Importantly, the programme also set out to establish if these benefits could be sustained after the programme had been completed.

The Sláintecare-funded projects contributed to a research fund, which enabled a jointly commissioned independent programme evaluation. This was led by Professor David Hevey, School of Psychology, Trinity College Dublin (TCD) and conducted during the Sláintecare implementation phase from August 2020 to December 2021. A multi-component, mixed method evaluation using the RE-AIM Framework tool (Glasgow 1999) was developed. This informed the feasibility of programme implementation within a community health model. Indicators were assessed using internationally validated measures where

available. Evidence was gathered from participants, Peer Leaders and programme staff. Data was gathered from participants at three time points:

T1. Pre-Living Well Programme (pre-LWP): in advance of Workshop 1.

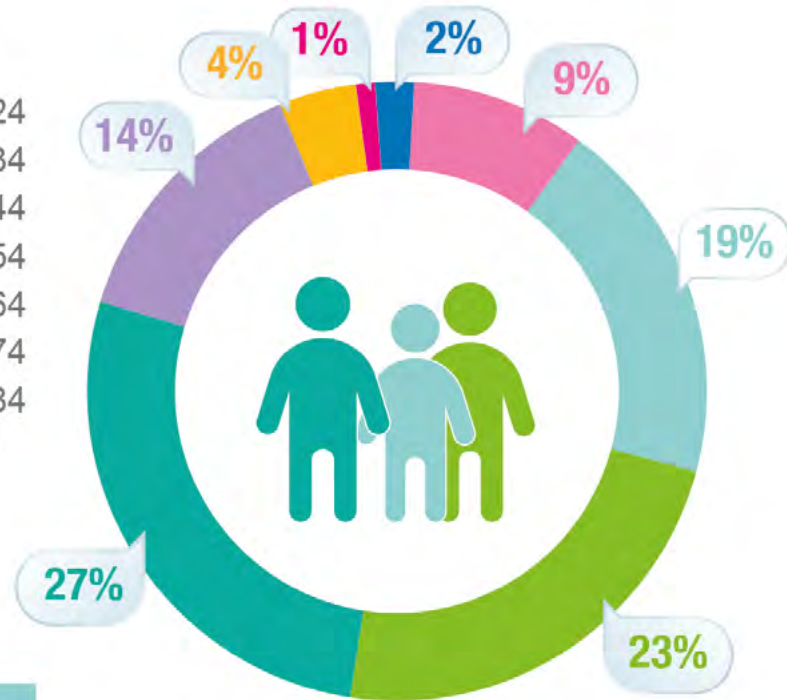
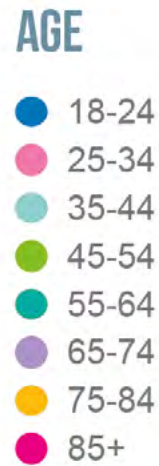
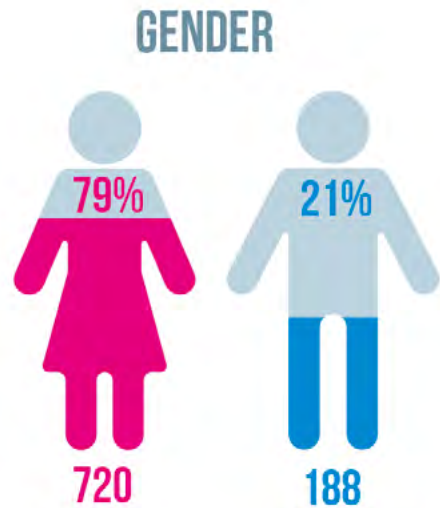
T2. Post-Living Well Programme (post-LWP): on completion of Workshop 6 (end of programme).

T3. 6 months post-Living Well Programme (6 months post-LWP) completion.

Table below shows survey response rates:

Survey Time Point	Number of eligible participants	Number of respondents	Response rate
T1.	1,482	913	62%
T2.	1,369	576	42%
T3.	1,024	336	33%

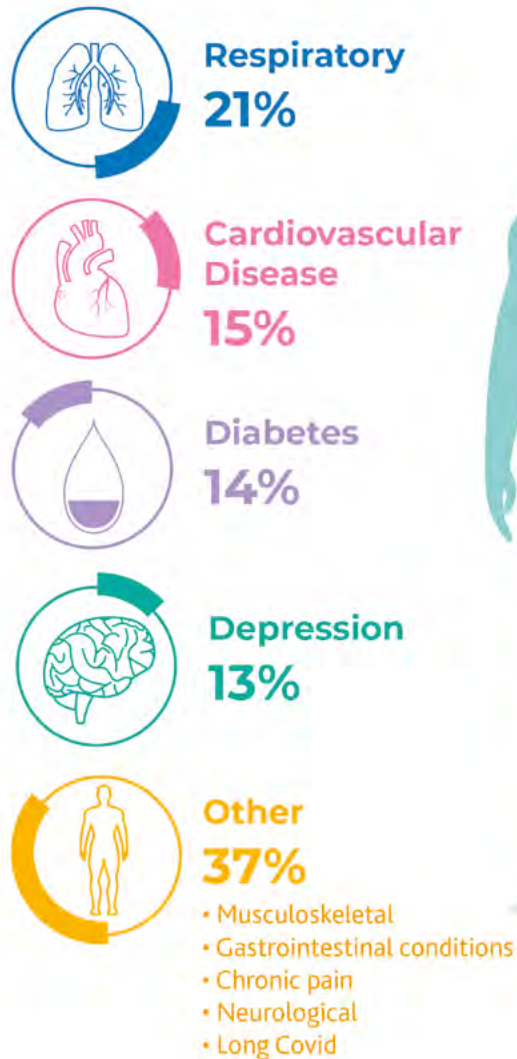
Profile of the participants at baseline



FULL MEDICAL CARD



Profile of chronic conditions of participants



ii. Your Voice Matters report:

In addition to the TCD evaluation findings, the Living Well Sláintecare project in HSE South East Community Healthcare (CHO 5) captured participant experiences through Your Voice Matters - a robust patient narrative framework tool. This provided a unique and innovative opportunity to use the power of participant stories for quality improvement and service redesign. Some of these testimonials are featured throughout this report.



DISCUSSION OF KEY FINDINGS

1. Participant satisfaction with the Living Well Programme and attendance rates

94% of participants were satisfied with the Living Well Programme, with 77% very satisfied.

Attendance at online Living Well workshops was consistently high among survey participants. 92% of respondents completed 4 or more of the 6 workshops. The completion rate compares favourably with international data on attendance rates for in person programmes of 75%.



"I felt so grateful to have a place on the course. I learnt so much from the course facilitators along with the other people on the course. There was a lovely warm and friendly atmosphere where people felt at ease being vulnerable and sharing personal experiences. Really helpful information delivered in a relaxed and relatable way."

"Without it I would still be sitting in sitting room watching the world go by from my window and my health go further down"



2. Opportunity for peer support and social connectedness

The Peer Leader model was highly valued by participants where Peer Leaders have a lived experience of chronic conditions and they model self-management strategies.

"I thought it was lovely and impactful that the Leaders were so open and honest and they also set goals and action plans every week so it felt that there was no judgement at all."
(Programme Participant)

"Our Leaders ...brought their own life experiences and health issues to the table which put us all on the same level and gave authenticity to their position."
(Programme Participant)

"The Leaders didn't just talk the talk, they walked the walk as they too live with pain and carry out positive actions to help."
(Programme Participant)

"It was so wonderful to have this support network for six weeks, taught by mentors who truly understand what it is like to live with a chronic, long-term condition"
(Programme Participant)

Peer Leaders also noted, "*the peer support aspect of the Living Well Programme was highly valued by participants as they realised that they are not alone in their struggles.*"

Peer Leaders, in turn, experience the empowerment associated with becoming a Leader and benefit from watching others flourish on their self-management journey.

Watch this short video (<https://youtu.be/84G8aPMerNU?si=nOY6fzr8Fs4zi8Kr>) courtesy of Martin, a previous participant and Mary, a Peer Leader, to hear more about these benefits.

Participants also highlighted the social aspect of the programme, and how it fosters a sense of "*connectedness*" and "*alleviates social isolation.*"

One Leader observed how the programme was a lifeline during the pandemic:

"It's been a true lifeline for many people as many have been quite lonely and have been afraid to go outside (during the Pandemic). Through the programme they're in the company of others with similar struggles and challenges which they find hugely comforting." (Peer Leader)

"As a Leader on the Living Well Programme, I find it very rewarding to see participants grow in confidence as they develop a sense of control over their health condition and their lives."
(Mary Shields, Peer Leader, Co Donegal)

3. Quality of life

There were statistically significant increases in health-related quality of life (HRQOL) from pre-LWP to post-LWP. Overall quality of life (QOL) increased significantly from pre-LWP to post-LWP (end of programme) and from pre-LWP to 6 months post-LWP (Appendix 2).

The changes in HRQOL may be associated with the positive increases in activity levels and self-efficacy, as well as the decreases in depression and social/role limitations due to illness attributed to participation in the Living Well Programme.

"Living Well gave me the confidence and information needed to improve my life. I am now back on track and enjoying life again." *Valerie, Co Donegal.*

"There was a great sense of being connected to a group...almost having a social life again." *Agnes, June 2021*

"Life isn't as scary anymore, thank you for that"
Participant.

"Over the six weeks I have become more aware of ways to self-manage my condition in a positive way to the best of my ability, even if I am curtailed or confined by my health condition." *Stacie.*

"I value my health so much more since completing this programme, it is the biggest gift I ever gave myself"
Participant.

"Thank you (to the LWP team). I am one starfish back in the ocean of life, and a grateful one I am."
Participant, June 2020



4. Exercise levels

There was a statistically significant increase in overall time spent doing aerobic exercise most significantly walking, from pre-LWP to post-LWP (end of programme) (Appendix 2).

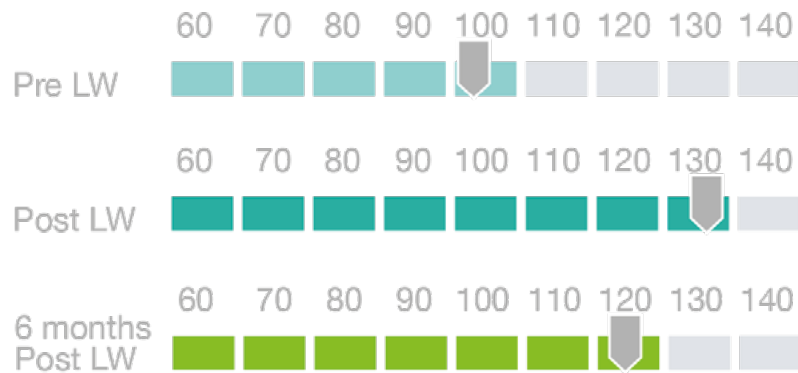
The relatively high baseline levels of exercise are noteworthy. However, evidence from Ipsos MRBI 2021 on behalf of Sport Ireland found

that there was a significant increase in numbers of adults walking for recreation during the pandemic lockdowns, when many other social activities were curtailed (Sport Ireland, 2021).

Participants reported the weekly action planning and reporting process within the programme was a motivating factor.



Aerobic exercise time (mins/week)



"The programme gave me the kick I needed to get me motivated to do something, I now go walking most days and exercise most mornings."

"I felt more motivated to carry out my action plan because partially I didn't want to let the group down."



5. Confidence to self-manage health

There were statistically significant increases in participant's self-efficacy for managing health from pre-LWP to post-LWP (end of programme) and from pre-LWP to 6 months post-LWP (Appendix 2).

Self Efficacy: Self-management (Self Rating Scale 0-10)



This is underpinned by qualitative responses from participants:

"I feel more in control of my illness now, having learned a number of self-management skills"

"I learned a lot from this programme, which gives me more confidence to self-manage my long-term health conditions and to focus on myself more"

"Safe to say the Living Well programme has been life changing for me...I've found myself again. I'm more confident, happier, determined and extremely motivated"



6. Confidence to engage with e-health interventions

Participant's confidence to take part in other online e-health programmes significantly increased after taking part in the Living Well Programme online, and this increase was sustained at six months (Appendix 2).

Self Efficacy: to take part in other e-health programmes (Self Rating Scale 0-10)



The observed increase in self-efficacy is potentially attributable to the participants' successful completion of the online Living Well Programme, with the support of the Living Well team. This provided a sense of mastery, which then made them more confident to be able to do other online programmes. This had a positive knock-on effect where people had more confidence to engage with virtual consultations and other e-health programmes available at that time, for example Diabetes Structured Patient Education.

"I feel empowered by the (digital) support."

"I learned a lot (about using Zoom) and now can do it by myself."



7. Perceptions of supports available to manage health

There was a statistically significant increase in participants' perception of support available to manage their health pre-LWP to post-LWP (end of programme) and from pre-LWP to 6 months post-LWP (Appendix 2).

The Living Well Programme places a significant emphasis on ensuring participants are familiar with community and wider system supports by the end of the programme. This is a key part of the programme to enable participants on their life-long self-management journey. The programme's resource table signposts participants to additional clinical and non-clinical sources of support for self-management, for example Social Prescribing services, voluntary organisations, peer support groups, exercise groups, healthy eating programmes, behaviour change support and mental health and wellbeing supports. It also included details of supports available during Covid-19.

"it really helped me to get the help that I needed"

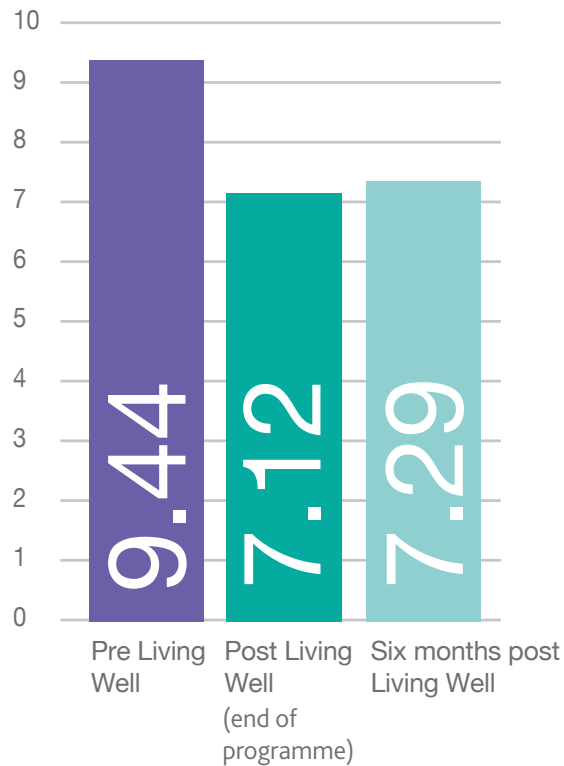
"I found the Living Well programme very helpful and informative... The information on diet, exercise, fatigue and getting help and advice and where to turn for this, very useful and helpful" (*Your Voice Matters* respondent)



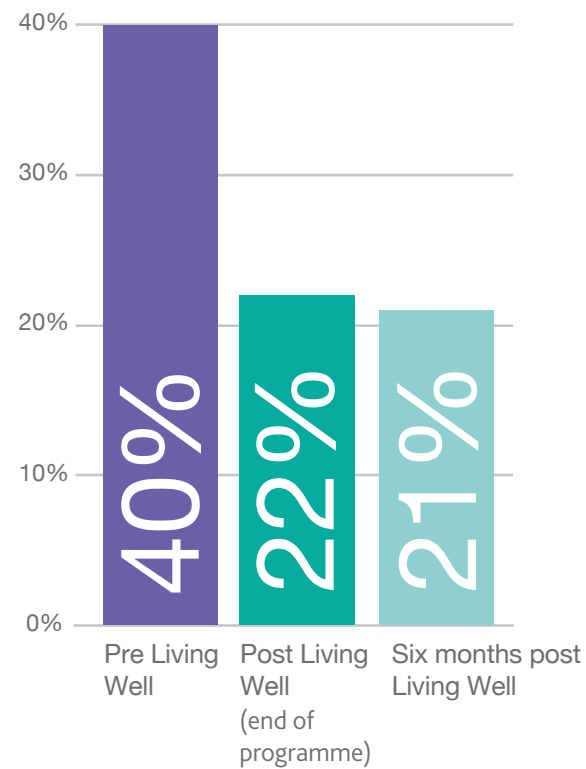
8. Levels of depression

There was a statistically significant decrease in depression levels from pre-LWP to post-LWP (end of programme) and from pre-LWP to 6 months post-LWP (Appendix 2).

Mean levels of depression over time
(PHQ-8 Self Rating Scale 0-10)



Percentage meeting criteria for clinical depression (PHQ-8)



8. Levels of depression

40% of participants met the PHQ-8 criteria for being in the clinical depression category at baseline. This fell significantly to 22% post-LWP (end of programme) and to 21% 6 months post-LWP.

The reduction in depression over the three time points indicates that the impact of the Living Well Programme goes beyond the immediate effect of the group support and that increasing capacity to self-manage physical health conditions has a direct bearing on levels of psychological distress.

The decrease in depression is consistent with previous research on CDSMP's beneficial effects on psychological distress (e.g. Campbell et al. 2021). The factors underlying the decrease in depression were not directly assessed but it is possible that the improvement in self-efficacy for managing health and the improvement in activity time were drivers of the reduced feelings of depression. Previous research has suggested that changes in self-efficacy are a plausible mechanism for decreasing depression (White, Kendrick & Yardley, 2009). In addition, there is good evidence for a relationship between greater physical activity and reduced depression symptoms (Dishman, McDowell & Herring, 2021; Schuch & Stubbs, 2019). The increased perception of support may also have contributed to the decrease in depression.

Living Well Programme Leaders noted *"participants make new friends during the six weeks, & the online social interaction alleviates social isolation."*

They also noted the programme fostered *"...improved communication skills to communicate not only with their health care professional but also family members".*

Programme Leaders also saw that as COVID-19 continued to impact on everyday life *"People needed Living Well more than ever...people felt isolated and vulnerable."*

*"In the middle of winter, in the middle of the dark months, in the middle of COVID-19 it brought some light, positivity and happiness to my life that I will continue to hold on to."
(Your Voice Matters respondent)*

"I have never done a course like this before. It was so truly enjoyable and I learnt so much about myself and living with my illness. Previously I would let my illness and symptoms consume me and it would greatly affect my mental state. I never realised there was a different way of thinking and managing my life. It never crossed my mind before that I could have an impact on my health. I really wish I had done something like this course ages ago!!! It had such a positive impact on my thinking, wellbeing, management."

9. Illness Interference with social role and employment role

There was a statistically significant decrease in the extent to which illness interfered in social activities, hobbies and work (where relevant) from pre-LWP to post-LWP (end of programme) and from pre-LWP to six months post-LWP (Appendix 2). The Living Well Programme supports participants to develop skills and utilise techniques to help them to self-manage symptoms and to actively problem-solve to address functional limitations arising from symptoms.

“Prior to starting the programme I often let my illness control aspects of my life and allowed it to interfere with my social life, my ability to exercise etc.... This programme provided strategies to overcome negativity and minimise the effect of the illness in my daily life.” (Your Voice Matters respondent)

‘The Living Well Programme helped me to build my confidence and self-esteem, I gained valuable experience with likeminded people, I had been unable to commit to work for over 10 years due to kidney disease. I have now gained employment in facilitating groups and this would not have been possible without my involvement with the Living Well Programme. Thanks very much.’ (Participant)

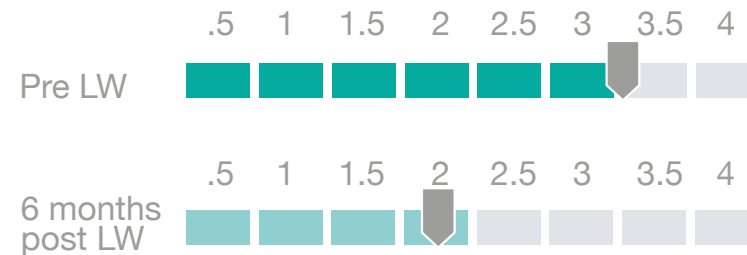
Delivering the Living Well Programme gave me back my confidence, it gave me a huge amount of fulfilment and purpose and the courage to get a part time job locally after many years of chronic illness.’ (Peer Leader, Cork)

10. Visits to GP

There was a statistically significant decrease in unscheduled visits to the GP from pre-LWP to 6 months post-LWP completion (representing a 35% decrease) (Appendix 2).



GP attendance (Mean no. GP visits in previous 6mth period)



The reduction in GP visits found in this study is an outcome which is consistent with evidence from the in-person CDSMP in Ireland in non-pandemic times (Hevey et al, 2020).

The Living Well Programme supports people to develop practical skills and confidence so they can better manage their health condition and make changes for a healthier life. Therefore, this improved self-management may reduce the need for the participant to attend their GP for symptom management.

The responses to the open-ended questions substantiated this:

In addition to this, participants reported increased confidence to communicate more effectively with their healthcare team. Programme Leaders noted that participants were helped to “make more of the time they get with their healthcare professional as they have a better idea of exactly what role everyone, including themselves, has to play.”

“I have learned that there are a lot of things which I can do to help myself live with Type 2 Diabetes and secondary cancer.”

“Living Well has given me the opportunity and support to learn and manage my condition very well, stay active and live well”

“The information given about diet, food labels and portion control in the programme was just what I needed, I am glad to say I have lost 2 and a half stone since which has a good knock on affect on my health”

“I feel more in control of my illness now, having learnt a number of self-management skills.”

“helped me to focus on managing my pain medication properly”

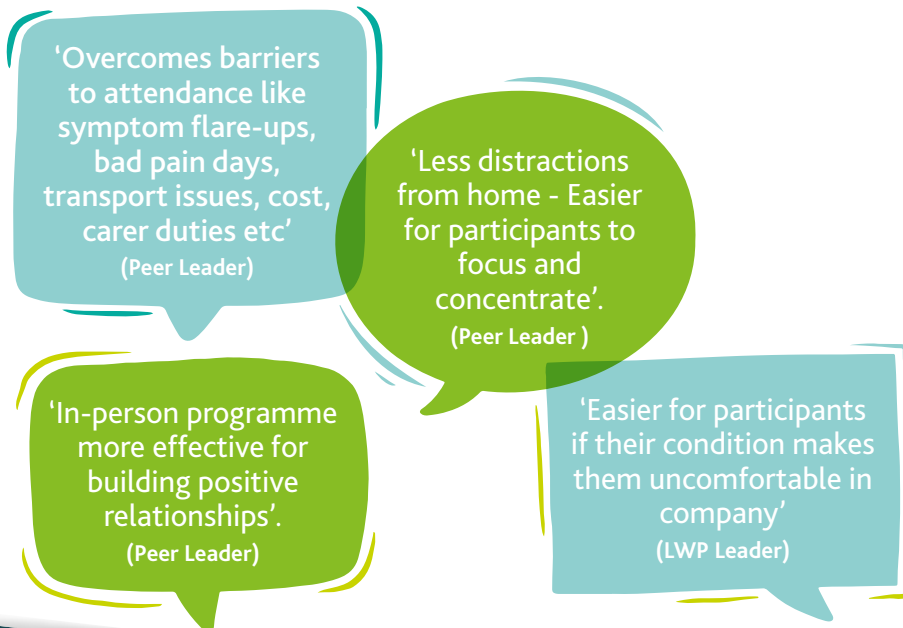
“thank you for giving me confidence and for helping/teaching me to manage my symptoms and cope better”

11. Building a responsive service

The online version of the programme was a response to an urgent need to provide support to people living with chronic health conditions during the COVID-19 pandemic. However, it was a new and unproven method of delivery, which warranted evaluation and testing of concept, which the research subsequently addressed.

The responses indicate that the majority of participants had a very positive experience with the online version. Others expressed a preference for in-person programmes. This diversity of preference is captured below, and has informed future planning where a hybrid model will be delivered with both in-person and online programmes available to suit participant choice.

Positives of online and in-person Living Well programmes



12. System level benefits

a. Adding value to the delivery of integrated care

As well as demonstrating the multiple benefits for people living with chronic health conditions, the evaluation identifies system-level benefits, and provides key insights into the successful delivery of the Living Well Programme in the health service. Key stakeholders in the delivery of the Living Well Programme (LWP Coordinators, SMS Coordinators and Peer Leaders) when consulted as part of the process evaluation, noted that programme participation facilitated:

"improved integration as participants are signposted to other supports over the course of the programme, including other telehealth and virtual supports for self-management."

"improved engagement and awareness of self-management support among health and social care professionals"

"reduced demand on health services with less visits to GP/hospitals unless really needed."

"Living Well Programme has the potential to assist participants to stay independent for longer, reducing avoidable costly health and social care provision." SMS Co-ordinator

Referrers to the Living Well Programme observed its effectiveness in increasing patients' confidence to self-manage:

"I have found programme graduates to be more resourceful and far more proactive in asking questions about their treatment protocols. Several patients have told me of the profound difference it (the LW Programme) has made to feel connected to others, who understand what it has been like to live in isolation and fear. To be able to do something proactive, to learn new skills, to connect with new people and to focus on what IS within their control has given many of my patients hope, where previously there was only fear, anxiety and depression." Rachel Dungan, Community Pharmacist, Waterford

"Our patients are now making choices to improve their health, becoming more active, eating more healthily and stopping smoking. They tell us that they are now comfortable with tasks such as taking medication, monitoring symptoms, coping with the emotional aspects of the condition. They have gained so much from the programme and we are very happy to be able to access the Living Well Programme for our members." Marcella Gemmill, Patient Services Co-ordinator, Irish Heart Foundation

"The Living Well Programme is a fantastic resource for clients with long-term chronic conditions and I fully endorse this programme to many of my clients. The positive benefits of this programme are reflected by clients becoming more empowered to manage their symptoms and rehab goals. The availability of this peer-led programme has enhanced my work in primary care." Dearhaile Oratis, Senior Physiotherapist, Dublin

b. Service-User Engagement

The Living Well Programme as a peer-to-peer support intervention aligns with the HSE Patient and Public Partnership Strategy recommendations for HSE services (HSE National Screening Service, 2019) where service-users themselves are leading in the delivery of support to peers. A service-user with chronic conditions was engaged in the planning and design of the research, as a member of the Research Advisory Group. Peer Leaders were also consulted about the design of the research and changes were implemented in response to their feedback. In addition, Peer Leaders' perspectives about the programme were captured through targeted focus groups.

CONCLUSIONS AND CONSIDERATIONS

Through the Sláintecare-funded proof of concept process, the Living Well Programme was mainstreamed in the six pilot CHOs. The independent research report makes a number of recommendations to ensure this groundwork is built upon including:

- Resourcing the delivery of the Living Well Programme nationally including national programme leadership
- Embedding the Living Well Programme in integrated care pathways

Suggested actions for key stakeholders:

1. Funding Commissioners:

- a. The evaluation demonstrates that the Living Well Programme is effective in supporting people living with chronic conditions to

self-manage, and the benefits of the programme are maintained over time. Resourcing the Living Well Programme as a national programme would support on the vision of Sláintecare by focusing on prevention and patient empowerment, helping to shift care from acute hospitals into the community setting.

- b. Resourcing the Living Well Programme at national level would also enable access for all adults with chronic conditions, removing the current geographical inequity, which is limiting the potential impact of the programme at scale. This would further support a reduction in the impact of chronic conditions on health service utilisation into the future.

2. HSE Leadership:

Embed the Living Well Programme within integrated care pathways for chronic disease management and older person services as a key resource to support patients to self-manage their chronic health conditions and stay well closer to home.

3. Health Care Professionals and Clinicians:

Promote, champion and refer their service-users to the Living Well Programme.

4. Community & Voluntary Sector:

Promote and champion the Living Well Programme among their service-users. Consider opportunities for embedding the Living Well Programme in their service delivery and support pathways.

GLOSSARY OF ACRONYMS AND TERMS

CDSMP:	Chronic Disease Self-Management Programme
CHO:	Community Healthcare Organisation
HSCPs:	Health and Social Care Professionals
HRQOL:	Health Related Quality of Life
HSE:	Health Service Executive
LWP:	Living Well Programme
PHQ:	Patient Health Questionnaire
SECH:	South East Community Healthcare
SIF:	Sláintecare Integration Fund
SMRC:	Self Management Resource Centre (in the US)
SMS:	Self-management Support

LWP Leaders: deliver the Living Well Programme. These are usually peers (referenced as **Peer Leaders**), but can also be health/social care professionals or Living Well Programme team members. All LWP Leaders attend standardised training to become accredited as leaders in the programme

LWP Master Trainers: they are qualified to train people to become Leaders. They can be peers or health / social care professionals, who have received additional train-the-trainer credentials

LWP Coordinators: coordinate the operational elements of the projects at CHO level

LWP Quality Support Mentors: trained to assess Leaders and provide quality support

Community Healthcare Organisations (CHOs)

CHO 1 Community Healthcare Cavan Donegal Leitrim Monaghan Sligo

CHO 2 Community Healthcare West (Galway, Mayo, Roscommon)

CHO 3 Mid-West Community Healthcare (Limerick, Clare and North Tipperary)

CHO 4 Cork-Kerry Community Healthcare

CHO 5 South East Community Healthcare (Carlow, Kilkenny, Wexford, Waterford, South Tipperary)

CHO 6 Community Healthcare East Wicklow, Dublin South and Dublin South East

CHO 7 Dublin South, Kildare & West Wicklow Community Healthcare

CHO 8 Midlands, Louth, Meath, Community Healthcare Organisation

CHO 9 Community Healthcare Organisation Dublin North City & County

REFERENCES:

Campbell D.; Wilson O'Raghallaigh, J.; O'Doherty V.; Lunt V.; Lowry D.; Mulhern S.; Lonergan K.; McSharry K.; Lynott J.; Forry M.; Evans D.; Pardoe P.; Ward H.; Hevey D. (2021) Investigating the impact of a chronic disease self-management programme on depression and quality of life scores in an Irish sample. *Psychology Health Med*, Apr 26:1-9, 10.1080/13548506.2021.1916953.

Dishman, R.K.; McDowell, C.P.; Herring, M.P. (2021) Customary physical activity and odds of depression: a systematic review and meta-analysis of 111 prospective cohort studies. *Br. J. Sports Med*, 10.1136/bjsports-2020-103140.

Health Service Executive (2020). National Framework for the integrated prevention and management of chronic disease in Ireland. Dublin.

Health Service Executive (2017). Living well with a chronic condition: framework for self-management support. Dublin.

HSE National Screening Service (2019). Patient and public partnership strategy 2019 - 2013. Dublin.

Hevey D.; Wilson O'Raghallaigh J.; O'Doherty V. et al. (2020) Pre-post effectiveness evaluation of Chronic Disease Self-Management Program (CDSMP) participation on health, well-being and health service utilization. *Chronic Illn*. Jun; 16(2), pp. 146-158.

Schuch, FB. Stubbs, B. (2019) The role of exercise in preventing and treating depression. *Curr. Sports Med. Rep.*, 18(8), pp. 299-30.

Sport Ireland (2021) Irish Sports Monitor Annual Report 2021. Dublin.

White, K., Kendrick, T., & Yardley, L. (2009). Change in self-esteem, self-efficacy and the mood dimensions of depression as potential mediators of the physical activity and depression relationship: Exploring the temporal relation of change. *Mental Health and Physical Activity*, 2(1), 44–52. <https://doi.org/10.1016/j.mhpa.2009.03.001>

APPENDIX 1

Self-management Support Coordinators

The 2017 National Framework for Self-management Support (SMS) was developed under the leadership of Dr. Orlaith O'Reilly, former National Clinical Advisor and Programme Group Lead for Chronic Disease and Dr. Carmel Mullaney, Specialist in Public Health Medicine. This framework provided an overview of the rationale and evidence for Self-management Support; including an implementation plan setting out how the HSE, working in partnership with key stakeholders, intends to implement self-management support for four major chronic conditions; COPD, Asthma, Diabetes and Cardiovascular Disease.

As per recommendation 7.2 of this framework, a Self-management Support Coordinator was appointed to each of the nine HSE CHOs to support the implementation of the Self-management Support Framework at CHO level.

The Self-management Support Coordinators were the Project Leads for the implementation of the Living Well Programme (LWP) during the Sláintecare Integration Fund period. They managed the operational, strategic and reporting elements of the Living Well Programmes at local and national levels. The Self-management Support Coordinators are now the service managers for the delivery of the LWP in their respective CHOs.

In addition to the LWP, their work portfolio includes the key workstreams below. For more information visit www.hse.ie/selfmanagementsupport

- **Raising awareness of the importance of self-management and self-management support** with Health and Social Care Professionals (HSCPs), patients and voluntary organisations.
- **Production and promotion of SMS Directories for Health and Social Care Professionals (HSCPs)** which signpost to resources

which can support patient self-management.

- **Development and maintenance of a dedicated SMS webpage for HSCPs** that details the resources and education programmes for Healthcare Professionals to support chronic disease management. Visit: Resources for Healthcare Professionals - HSE.ie
- **Production and promotion of SMS patient resources** including leaflets and videos, which support people to self-manage their chronic conditions and reduce the risk of developing complications or co-morbidities.
- **Development and maintenance of a dedicated SMS webpage for patients** living with chronic conditions which details the clinically approved resources, programmes and services which support self-management. Visit: Resources for People living with a Long-term Health Condition - HSE.ie
- **Embedding SMS within integrated care pathways for Chronic Disease and Older Persons** through SMS Coordinator membership in local integrated care implementation structures as part of the Enhanced Community Care Programme.
- **Cross-sectoral collaboration with condition-specific Voluntary Organisations (COPD Support Ireland, Asthma Society of Ireland, Croí, Irish Heart Foundation, Diabetes Ireland)**
 - Development, support and promotion of condition-specific Peer Support Groups (Cardiac, Stroke, COPD)
 - Assistance with development and promotion of their patient resources
 - Promotion of HSE programmes and resources which support self-management to their members

APPENDIX 2

Outcomes Summary Table

	Assessed using:	Baseline (T1)	T2	T3	Effect size	p-Value
Quality of Life (QoL)	Single item 7 point scale	4.05 (1.38)	4.66 (1.25)	4.45 (1.36)	T1-T2: 0.44 T1-T3: 0.29	<.001 <.001
Health-related QoL (N = 99)	The EQ-5D (Devlin & Brooks, 2017) visual Analogue Scale (0 – 100) as a self-reported global measure of overall health.	59.91 (19.91)	64.64 (20.46)		0.24	.001
Confidence to self-manage health condition	10 point self-efficacy for illness management scale	5.31 (2.77)	7.48 (1.83)	7.40 (2.01)	T1-T2: 0.78 T1-T3: 0.75	<.001 <.001
Exercise levels	Exercise behaviour scale:	104.71 (93.53)	136.73 (107.16)	123.46 (96.33)	T1-T2: 0.34 T1-T3: 0.20	<.05 NS
	Aerobic exercise Walking	86.58 (67.98)	101.49 (68.69)	89.69 (67.81)	T1-T2: 0.22* T1-T3: 0.05	.01 NS
Confidence to engage with e-health intervention	10 point confidence scale.	4.72 (3.39)	8.25 (2.00)	7.93 (2.20)	T1-T2: 1.04 T1-T3: 0.95	<.001 <.001

Outcomes Summary Table (contd.)

Perceptions of supports available to manage health	Single item 5 point satisfaction scale.	3.20 (1.24)	3.52 (1.19)	3.59 (1.27)	T1-T2: 0.26 T1-T3: 0.31	<.001 <.001
Levels of depression	PHQ-8 (Kroenke et al. 2009) 8 item scale.	9.44 (5.94)	7.12 (5.12)	7.29 (5.52)	T1-T2: 0.39 T1-T3: 0.36	<.001 <.001
Illness interference with social role: (Normal social & Hobbies)	2-item scale adapted from the Medical Outcomes Study (Tarlov et al. 1989)	1.93 (1.33)	1.60 (1.33)	1.50 (1.32)	T1-T2: 0.25 T1-T3: 0.32	<.001 <.001
		2.05 (1.39)	1.72 (1.32)	1.58 (1.31)	T1-T2: 0.24 T1-T3: 0.34	.001 <.001
Illness interference with employment role (N = 102)	Scale adapted from the Medical Outcomes Study (Tarlov et al. 1989)	1.31 (1.28)	0.74 (1.08)	1.01 (1.13)	T1-T2: 0.44 T1-T3: 0.23	<.001 <.01
GP attendance rate	Self-rated GP attendance in the previous six months	<u>M (SD)</u> 3.13 (2.9)		2.03** (2.1)		<.01 (non-parametric)

Living Well Programme Podcast

In this podcast, Tommy shares his experience of participating in the Living Well Programme, his personal challenges and how the programme offered practical help and support. Liz Cox, a Living Well Leader, talks to us about the structure of the programme and what people can expect. Mary Gowing, a HSE Self-management Support Coordinator discusses the history of the Living Well Programme, its origins and explains more about what a long-term health condition is.

Podcast link:

<https://www.youtube.com/watch?v=Jd9TXot-PzA>



Visit the Living Well
Programme webpage at
www.hse.ie/LivingWell
or scan this QR code:

