



Regional Evaluation of a self-management tool for people living with long-term conditions: A participatory approach



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SUMMARY

MyLifeTool is a self-management tool for people living with any long-term condition (LTC). It was developed in partnership with people living with LTCs and encourages people to think about their strengths and how to self-manage their LTC in ways that fit with their own lifestyles and future plans. It supports people to reflect on how to self-manage the physical, psychological and social effects of their LTC. Throughout the project, eight people with LTCs worked in partnership with us as Participatory Research Associates (PRAs).

This project aimed to evaluate the effectiveness and experiences of using MyLifeTool. 30 people living with different LTCs used MyLifeTool for twelve weeks and completed an online questionnaire at the start of the project, at week six and at week twelve. At week twelve, they were asked to write down their thoughts, perceptions and experiences of using MyLifeTool. Six of the 30 people who took part were also interviewed at the end of the twelve weeks to find out more about their experience of using MyLifeTool.

MyLifeTool significantly increased participants' well-being, their sense of control over their LTC and how to self-manage their LTC, and their ability to pace themselves. Using the tool also significantly reduced the amount they felt their LTC took over their lives. Participants told us that MyLifeTool supported them to reflect on their LTC and self-management experience and helped them to accept their condition and develop positive coping strategies. The next steps include testing the effectiveness of MyLifeTool on a larger group of people from across the UK and develop an online version of the tool.



INTRODUCTION

This project was funded by the National Institute for Health and Care Research (NIHR) Applied Research Collaboration (ARC) North East and North Cumbria (NENC) and was conducted in partnership between academics at Teesside University and representatives of Neuro Key (a North East based charity who support people who live or care for someone with a neurological condition). The project used a participatory action research (PAR) approach, where eight people living with LTCs worked as Participatory Research Associates (PRAs) to design the project, introduce participants to MyLifeTool, analyse the data and present the findings at a conference.

Long-term conditions and self-management

Approximately 26 million people in the UK live with an LTC¹ and many experience poor quality of life, depression and anxiety². Interventions used to support people with LTCs tend to focus on medical outcomes, such as experiencing few or less severe symptoms³. However, this approach does not consider how living with an LTC affects a person's life, how they see themselves and how they interact with other people. Research suggests that self-management interventions for people with LTCs should support people to develop their own strategies and resources that meet their own needs and fit within their lives⁴.

What is MyLifeTool?

MyLifeTool is a self-management tool designed to improve the well-being of people living with LTCs. It was developed by people living with LTCs. It consists of seven booklets: My Journey; My Scrapbook; five My Toolbox booklets (Me and my condition, Embracing my body, Taking charge, Connecting with others and What's important to

1. Sanderson, J. & White, J. (2018). *Making the case for the personalised approach*. NHS England
2. Naylor, C., Parsonage, M., McDaid, D., Knapp, M., Fossey, M., & Galea, A. (2012). Long-term conditions and mental health: The cost of co-morbidities. *King's Fund* (London, England).
3. Audulv, A., Packer, T., Hutchinson, S., Roger, K. S., & Kephart, G. (2016). Coping, adapting or self-managing - what is the difference? A concept review based on the neurological literature. *Journal of Advanced Nursing*, 72(11), 2629-2643. <https://doi.org/10.1111/jan.13037>
4. Jackson, K., Hamilton, S., Jones, S., & Barr, S. (2019). Patient reported experiences of using community rehabilitation and/or support services whilst living with a long-term neurological condition: A qualitative systematic review and meta-aggregation. *Disability and Rehabilitation*, 41(23), 2731-2749. <https://doi.org/10.1080/09638288.2018.1473508>



me) (figure 1). The activities included in MyLifeTool have been adapted from occupational health techniques and include developing resilience, goal setting, planning and pacing. These activities support people to reflect on what does and does not work for them. MyLifeTool is based on a self-management framework developed by the research team⁵.

Figure 1: MyLifeTool



1. **Me and my condition** focuses on identity, how you see yourself and how you manage expectations of yourself.
2. **Embracing my body** involves paying attention to signs and symptoms of your LTCs, planning, pacing and energy conservation.
3. **Taking charge** is considered with learning about your condition, building resilience and goal setting.
4. **Connecting with others** emphasises exploring support options, asking for support and supporting others.
5. **What's important to me** is about finding time for yourself and identifying what gives you meaning and purpose in life.

5. Kılınc, S., Erdem, H., Healey, R., & Cole, J. (2020). "Finding meaning and purpose": A framework for the self-management of neurological conditions. *Disability and Rehabilitation*, 44(2), 219-230. <https://doi.org/10.1080/09638288.2020.1764115>

WHAT WE DID

Project aims

Integrating MyLifeTool into long-term condition services has the potential to provide an approach to LTC self-management that addresses the psychological needs of people living with LTCs. The aim of the project was to evaluate the effectiveness and experiences of using MyLifeTool, in the hope that we could provide evidence to support using MyLifeTool in LTC services across the North East and North Cumbria region and in the future, across the UK.

Method

People with LTCs used MyLifeTool for twelve weeks and completed an online questionnaire at the start of the project, at week six and at week twelve. At week twelve, they were asked to write down their thoughts, perceptions and experiences of using MyLifeTool. Some were also interviewed at the end of the twelve weeks to find out more about their experience of using MyLifeTool.

Thirty people living with LTCs took part in the project. We included people who lived with physical, neurological, neurodevelopmental and mental health conditions, so participants lived with LTCs such as anxiety, arthritis, asthma, autism spectrum disorder, chronic fatigue syndrome, depression, diabetes, irritable bowel syndrome, multiple sclerosis, obsessive compulsive disorder, Parkinson's disease and psoriasis. Participants had lived with their LTCs from less than one year and up to more than twenty years.



WHAT WE FOUND

Using MyLifeTool for twelve weeks significantly increased participants' well-being, their ability to pace themselves, their sense of control over their LTC and how to self-manage their LTC. Using the tool also significantly reduced the amount they felt their LTC took over their lives.

Figure 2: Key findings





Participants told us that MyLifeTool supported them to reflect on their LTC and self-management experience and helped them to accept their condition and develop positive coping strategies:

Changing behaviour and building skills

Participants explained how using MyLifeTool can increase positive self-management behaviours such as pacing, engaging in physical and emotional well-being activities and improving ability to establish achievable goals.

Personalised approach

Participants liked the way that MyLifeTool supported them to understand what they were capable of doing and how to focus on their strengths and how to use those strengths to help self-manage their condition.

Reflection as a powerful tool

MyLifeTool encourages people with LTCs to reflect on their strengths and what does and does not support their self-management. This feature was described by participants as helpful and something that supported them on their journey to accept their condition.

Personal growth

Participants described how using MyLifeTool enabled them to seize opportunities and supported positive behaviour change. Part of this was engaging with peer support.

Mode of delivery

Although some participants liked using the printed booklets, others would have preferred an online version of MyLifeTool, like a mobile app. Some participants also felt that professional support would also increase the impact of the MyLifeTool.



CONCLUSIONS AND NEXT STEPS

Conclusions

MyLifeTool can support people with LTCs to reflect on what self-management and coping strategies do and do not work for them. It enables people to reflect on their strengths and how to use those strengths to support their self-management. As a result, MyLifeTool increases people's well-being, their ability to pace themselves and their sense of control over their LTC and how to self-manage their LTC. The tool also supports people with LTCs on their journey towards accepting their condition(s).

Next steps

The positive results from this project will be used to support the development of a larger, UK-wide evaluation of MyLifeTool. Based on participant feedback, we will also look for funding to develop an online version of MyLifeTool.



**MyLifeTool is freely available
to download from
www.mylifetool.co.uk**



If you would like any further information,
please contact Dr Stephanie Kılınc at
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