

Impact case study (REF3)

Institution: Teesside University		
Unit of Assessment: 4		
Title of case study: Helping people with long-term health conditions and their health professionals improve self-management, function and wellbeing		
Period when the underpinning research was undertaken:		
Details of staff conducting the underpinning research from the submitting unit:		
Name(s):	Role(s) (e.g. job title):	Period(s) employed by submitting HEI:
Alison Guy Lis Hammond	Deputy Dean Senior Lecturer in Counselling Psychology	Feb 2010 to Dec 2017 Aug 2015 to Aug 2019
Sarah Hirst-Winthrop	Principal Lecturer in Counselling Psychology	Nov 2002 to Feb 2014
Stephanie Kılınc Anna van Wersch	Senior Lecturer in Psychology Professor in Psychology	Nov 2002 to present Sep 1997 to Jul 2017
Period when the claimed impact occurred: August 2013 to 2020		
Is this case study continued from a case study submitted in 2014? No		

1. Summary of the impact (indicative maximum 100 words)

Research conducted at the Centre for Applied Psychological Science at Teesside University has informed the practice of health-care practitioners working with people with long-term conditions and has also led to changes in the techniques people with long-term conditions use to self-manage their condition. Ultimately these changes have improved this client group's function and wellbeing. Specifically, research has led to a change in the clinical practice of health-care practitioners, a change in the way those with long term conditions manage their condition through the adoption of a research-informed self-management tool, and also a change to national and regional service-user organisations' practice in supporting those with long term conditions (Neuro Key, The Brain and Spine Foundation, Therapeutic Care Volunteers, The Stroke Association – North Yorkshire and Teesside).

2. Underpinning research (indicative maximum 500 words)

Nationally, people with long-term conditions (LTCs) account for 70% of NHS spending and estimates suggest that 20-30% of patients attending specialist services need professional support to change their health behaviour to accommodate their LTCs (Mitchell et al, 2011). Regionally, the North-east of England, where Teesside University is located, has the highest rate of LTCs (Jagger, 2014) and the highest rate of activity-limiting long-lasting health problems and disabilities (Office of National Statistics, 2013). To address this health and wellbeing issue the underpinning research investigated the experience of living with LTCs and developed a self-management framework and integrative model of adjustment to chronic conditions.

Researchers at the Centre for Applied Psychological Science (Hirst-Winthrop, Hammond) conducted a grounded theory study focussing on adjustment to living with type-2 diabetes [3.1]. Analysis of interview and focus group data led to the development of the first integrative process model of adjustment to chronic conditions (IMACC). IMACC describes the normative process of psychosocial adjustment in type-2 diabetes both over time and in moments of challenge from both internal and external stressors. The model, which is based on biopsychosocial principles, is characterised by three levels: pre-morbid personality, on-going adjustment cycle, and maintenance cycle. This research was carried out and first published between September 2008 and August 2016. To demonstrate the applicability of IMACC beyond type-2 diabetes, qualitative data was analysed on the experience of adult-onset epilepsy in 2017 [3.2]. The results, published in 2019, revealed that the IMACC model was applicable to this new client group after only minor revisions to the model. Collectively these findings support the IMACC model for use

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as a clinical intervention and as such the research is directly applicable to the clinical practice of health care practitioners working with people with LTCs.

Self-management has also been heralded as the way forward in improving health outcomes for those living with LTCs (National Institute for Health and Care Excellence, 2012). Research on the lived experience of people with LTCs led to the development of a new self-management framework. Semi-structured interviews were used to examine the experience of 39 adults living with epilepsy following diagnosis in adulthood [3.3]. The results identified issues relating to re-evaluation of the individual's future and were pivotal in highlighting that those living with adult-onset epilepsy have a specific experience of the condition and support needs. These findings were supported by study [3.4] which revealed that living with adult-onset epilepsy can challenge a person's sense of self and trust in their body, resulting in the adoption of various strategies to manage the threat to their identity. More recently, research explored how people with adult-onset epilepsy experience healthcare services [3.5]. It was found that healthcare professionals focus too heavily on the medical management of epilepsy and overlook how the condition and treatment regime fit into a person's life. This can have a detrimental effect on self-management of their condition. Taken together these findings are significant. They recommend practitioners consider the specific impact adult-onset epilepsy can have on a person's behaviour and wellbeing. They highlight the profound, negative impact of the condition on how people live their lives, their experience of their body and their identity, as well as the need to capture service-users' voices and their lived experiences as a means to identify their support needs and affect change within existing service structures.

Based on these findings, research was then conducted in collaboration with Neuro Key (working title of the Tees Valley, Durham and North Yorkshire Neurological Alliance - a charity dedicated to improving the lives of people with neurological conditions) to examine the self-management of LTCs. Using a qualitative, phenomenological approach, which recognised service users as the experts on their conditions, the research examined the experience of self-management and feasibility of exploring self-management across neurological conditions [3.6]. Two themes were identified. First, achieving meaning and purpose in life is central to self-management and can be realised by considering what is important to me; me and my condition; embracing my body; connecting with others and taking charge. Second, "finding the new normal" emphasised the centrality of reflection in an on-going self-management process. This research was the first to develop a pan-condition self-management framework for long-term neurological conditions, underpinned by positive psychology and has since been developed into a new self-management tool (SMT) and programme for people with LTCs.

3. References to the research (indicative maximum of six references)

- [3.1] Hammond LD, Hirst-Winthrop S. 2016. Proposal of an integrative model of adjustment to chronic conditions: An understanding of the process of psychosocial adjustment to living with type 2 diabetes. *Journal of Health Psychology*. 23:8, 1063-1074. <https://doi.org/10.1177/1359105316664131>.
- [3.2] Hammond LD, Farrington A, Kılınç S. 2019. Validation of the integrative model of adjustment to chronic conditions: Applicability to adult-onset epilepsy. *Health Psychology Open*. 6:2. <https://doi.org/10.1177/2055102919884293>.
- [3.3] Kılınç S, van Wersch A, Campbell C, Guy A. 2017. The experience of living with adult-onset epilepsy. *Epilepsy and Behavior*. 73, 189-196. <https://doi.org/10.1016/j.yebeh.2017.05.038>.
- [3.4] Kılınç S, Campbell C, Guy A, & van Wersch A. 2018. Epilepsy, identity and the experience of the body. *Epilepsy and Behavior*. 89, 42-47. <https://doi.org/10.1016/j.yebeh.2018.10.003>. Selected for REF2021.
- [3.5] Kılınç, S, Campbell C, Guy A, & van Wersch A. 2020. Negotiating the boundaries of the medical model: Experiences of people with epilepsy. *Epilepsy and Behavior*. 102, 106674. <https://doi.org/10.1016/j.yebeh.2019.106674>.

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[3.6] Kiliç S, Erdem H, Healey R, Cole J. 2020. Finding Meaning and Purpose: A Framework for the Self-Management of Neurological Conditions. *Disability and Rehabilitation*. <https://doi.org/10.1080/09638288.2020.1764115>. Selected for REF2021.

All articles have been peer-reviewed for publication in high-quality journals focusing on health psychology, and specialist health and rehabilitation journals for a clinical audience.

4. Details of the impact (indicative maximum 750 words)

The underpinning research has achieved impact at three levels. First, it has led to a change in the clinical practice of health-care practitioners (HCPs). Second, it has led to a change in the way people with LTCs manage their condition to improve their wellbeing and function. Third, it has led to a change in service-user organisations' practice in supporting people with LTCs.

The underpinning research has changed the clinical practice of health care practitioners. Diagnosis with a LTC usually requires a lifestyle change. Successful psychosocial adjustment is important for optimal management of LTCs, but also for adequate physical and emotional functioning and quality of life. The IMACC model [3.1 and 3.2] provided practitioners with a new framework to use when supporting people with LTCs to adjust to their condition. Within this REF impact period, IMACC has been used by a broad range of HCPs working within NHS trusts and private healthcare organisations including psychological wellbeing practitioners, counsellors, high intensity CBT trainees and practitioners, clinical and counselling psychologists, physiotherapists and interpersonal psychotherapists. These practitioners have used IMACC to support patients with various conditions (e.g. chronic and neuropathic pain, auto-immune inflammatory condition, chronic fatigue syndrome, fibromyalgia and lower limb amputation) and it has been used in both one-to-one and group sessions [5.1]. Individual HCPs who use IMACC have explained exactly how the model has changed and benefited their practice, one stating that they have integrated it into their practice as 'an early intervention' and a counselling psychologist saying 'it has impacted on the way I formulate chronic pain presentations and the way in which symptoms are conceptualised with the client' [5.1]. Not only have HCPs and their clients benefited from using IMACC in their own practice, they have also trained other HCPs in the use of the model. For example, a clinical psychologist has 'used the model to provide some training to a group of cardiac rehab nurses' [5.1]. This feedback from HCPs demonstrates both the adoption of IMACC [3.1 and 3.2] by clinical practitioners and the benefits of doing so for both themselves and their clients.

At a service level, HCPs in the multidisciplinary pain management team at County Durham and Darlington NHS Foundation Trust began using IMACC in their clinical practice in 2010 after attending a presentation on the IMACC research project, and have continued to use IMACC during this REF period. Psychologists in this team used the model to inform assessment and therapy with individual patients and it also informed the development of a group session on adjustment. A psychologist from the team stated that: 'I would have struggled to work in pain management without IMACC holding everything together for me' [5.2]. The senior physiotherapist and occupational therapist also used IMACC to inform assessment procedures, integrating the model into their routine assessment practice. This multidisciplinary team estimate that IMACC has been used to inform assessment and treatment for more than 2,000 patients with a psychologist reporting use of IMACC with 70-80% of her caseload [5.2].

Alliance Psychological Services Ltd (APS) have also adopted IMACC in their clinical practice. APS are the largest counselling and psychological therapies provider in Teesside. They provide specialist services to support children, young people and adults and offer employee wellbeing support to organisations. APS have approved the IMACC model for staff who have completed the basic IMACC training and, where appropriate to do so, implement the model or parts of the model within their practice on a service level for staff working with LTCs [5.3]. For a senior therapist at APS, IMACC has benefited their practice: 'I mainly use the model during assessments to help isolate specific areas of development with my clients. I do find it very helpful to navigate where the client may feel stuck and to help to develop a collaborative goal' [5.3]. A counsellor at APS also found the IMACC maintenance cycle formulation 'helpful in identifying the client's current challenges in their life' and to 'adjust the therapeutic inputs, accordingly' [5.3]. Adoption of IMACC within their practice has also benefited the clients of APS

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as ‘clients found it useful in helping manage their symptoms of pain and began “pacing” more effectively’ [5.3].

The underpinning research has also changed the way people with LTCs self-manage their condition to improve their wellbeing and function. In collaboration with Neuro Key, findings from the research [3.3, 3.4, 3.5, 3.6] were used to develop a new self-management tool. MyLifeTool was launched by Neuro Key in October 2019 [5.4]. A support programme for the tool, MyCreativeLife, was piloted with Neuro Key between January and March 2020 and was formally released in December 2020 [5.4]. The tool and support programme focus on the key principles identified in the self-management framework [3.6]. The MyLifeTool can be downloaded from Neuro Key’s website or professionally printed booklets can be provided to people with LTCs and organisations that support them. For the co-founder of Neuro Key: ‘people who have used the tool have reported increased confidence in meeting new people, a more positive outlook that recognises their achievements and ability to face challenges associated with their condition with more effective use of goal-setting, planning and pacing strategies’ [5.5]. The research finding that achieving meaning and purpose is central to successful self-management for people with LTCs [3.5] has also led to Neuro Key offering more participatory experiences for clients based on the research [3.5]: ‘the research has not only impacted on the organisation, but has also had an impact on the psychological wellbeing of service users who have taken on these roles...one of the primary benefits is that participants can make their existence count for someone else’ [5.5]. For participant peer mentors on the 2020 pilot programme undertaken with Neuro Key, the role positively influenced their wellbeing and ‘reinforced that anything’s possible’, helping them to recognise the journey they have gone through in managing their own LTC [5.6, p. 29]. As one peer mentor states: ‘when you’re listening to these participants you think ‘ah, I was there once...and then look how this journey has come on. And it is different, it is better, it is positive’ [5.6, p. 29]. Overall, the research developed at Teesside University has provided Neuro Key with ‘a mechanism to improve their service delivery by which their beneficiaries gain value in their day-to-day lives’ [5.5]. In addition, it led in October 2020 to Neuro Key securing funding from Middlesbrough Council to extend their use of the tool to carers of people with LTCs [5.5].

The tool and underpinning research have also led to changes in practice at several service-user organisations that support people with LTCs, including Mind (Middlesbrough and Stockton), the Brain and Spine Foundation, and the Therapeutic Care Volunteers at James Cook University Hospital.

The Therapeutic Care Team at James Cook University Hospital were introduced to the MyLifeTool in October 2019. Following a training session with Kılınc, therapeutic care volunteers were encouraged to use the MyLifeTool in their work at the hospital. For the lead nurse therapeutic support at James Cook University Hospital: ‘the MyLifeTool has been used as an excellent prompt for patient care, the elements included have allowed staff to explore a holistic assessment of the patient’s emotional wellbeing. Some volunteers have been able to use the tool to gain great insight into the patients need’ [5.7]. For a social prescribing link worker at Middlesbrough and Stockton Mind, the tool has been used as a ‘guided self-help tool’ and was thought to be ‘very user friendly and accessible’, incorporating ‘many techniques, interventions and tools all in one place and clients have also offered positive feedback about the content and usability to support clients’ [5.8]. Following a pilot with the Brain and Spine Foundation in July 2020, the foundation adopted the tool for use with their Neuro Social Groups led by experienced practitioners [5.9]. For the services development lead, ‘the self-management framework and programme has offered us a new way to support our service users to self-manage their condition, in a way that will have significant benefit for the people who use our charity’s services’ [5.9].

A qualitative evaluation of the MyLifeTool and MyCreativeLife support programme was undertaken between September 2019 and March 2020 and submitted as a final report to Neuro Key in February 2021. Eight people with LTCs took part in the evaluation of the tool, seven in the evaluation of the support programme, and an additional two peer mentors were interviewed as part of the assessment of the programme implementation. Participants reported that the tool supported them to feel more positive about themselves and their condition. For one participant, the tool ‘was beneficial for my self-esteem and self-efficacy as I have a tendency to look at any

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efforts I make negatively. My internal beliefs surrounding my levels of maturity, productivity and capabilities with completing tasks are always derogatory/negative in content. The list gave me the visual to gain insight into why others point out my resilience and tendency to rationally look at situations and act productively' [5.6, p. 8]. For another, the tool gave them 'the opportunity to identify why I have been experiencing certain difficulties over my life. I have identified looking over the content and considering why I have used the scrapbook on these days that I have the inability to experience certain emotional responses. This led me to reach out to the appropriate professionals' [5.6. p.10]. And for another: 'it's kind of also about like self-awareness as well and I think that's kind of developed with the tool because obviously you're looking at your condition with a like kind of with a magnifying glass d'you know what I mean so it's becoming more aware of it and how it works and when the warning signs are and things like that so it's really helped' [5.6, p. 14].

5. Sources to corroborate the impact (indicative maximum of 10 references)

[5.1] Collated email and social media correspondence (pdf). Feedback from seven health care practitioners who use IMACC in their clinical practice. Correspondence received between February 2019 and June 2020.

[5.2] Collated email correspondence (pdf). Feedback from three members of the MDT Pain Management Service (County Durham & Darlington NHS Foundation Trust's Pain Management Service). Correspondence received between 4 April 2018 and 31 August 2018.

[5.3] Collated email correspondence and formal evaluation (pdf) from Alliance Psychological Services Ltd. Correspondence received between 30 September 2019 and 25 February 2020.

[5.4] Press Release (pdf) by Neuro Key for [MyLifeTool](#) (5 October 2019) and [MyCreativeLife](#) (21 December 2020). The website includes information on the tool and the support programme MyCreativeLife. The tool is available at: <http://www.mylifetool.co.uk/> and on the Neuro Key website: <https://www.na-tvdny.org.uk/resource/mylifetool/>

[5.5] Signed Letter (pdf). Testimonial from Neuro Key Head of Operations. Received 16 March 2021.

[5.6] Project Report (pdf). Kılınç, S. 2021. The impact of MyLifeTool and MyCreativeLife on the function and wellbeing of people with long-term conditions. Teesside University. This report contains extracts from interviews and focus groups with people with LTCs who have used the tool and programme as well as peer mentors on the programme. Responses were collected between 2019 and 2020.

[5.7] Signed Letter (pdf). Testimonial from the lead nurse therapeutic support at South Tees Hospitals NHS Trust. Received 8 December 2020.

[5.8] Email correspondence (pdf). Feedback on MyLifeTool from social prescribing link worker at Middlesbrough and Stockton Mind. Received 21 December 2020.

[5.9] Signed Letter (pdf). Testimonial from the services development lead at The Brain and Spine Foundation. Received December 2020.