

<b>Institution:</b> University of Leeds		
<b>Unit of Assessment:</b> UoA24 Sports and Exercise Sciences, Leisure and Tourism		
<b>Title of case study:</b> 'Move to Improve': Promoting physical activity in rehabilitative palliative cancer care.		
<b>Period when the underpinning research was undertaken:</b> 2011– present		
<b>Details of staff conducting the underpinning research from the submitting unit:</b>		
<b>Name(s):</b>	<b>Role(s) (e.g. job title):</b>	<b>Period(s) employed by submitting HEI:</b>
Dr Shaunna Burke	Associate Professor in Exercise and Health Psychology	2011-present
<b>Period when the claimed impact occurred:</b> 1 <sup>st</sup> January 2019 – 31st December 2020		
<b>Is this case study continued from a case study submitted in 2014?</b> N		
<p><b>1. Summary of the impact</b> (indicative maximum 100 words)</p> <p><b>Burke's</b> research has led to the development and testing of an innovative 'Move to Improve' toolkit to promote and embed physical activity (PA) in rehabilitative palliative cancer care, which has: (a) improved patients' functional mobility and understanding of PA; (b) increased healthcare providers' knowledge and delivery of PA in routine care and (c); guided organizational PA strategies/policies and staff training. 'Move to Improve' has been tested in clinical practice and adopted by 7 Sue Ryder hospices (UK) and Dr. Sardjito General Hospital (Indonesia). These establishments employ approximately 1000 staff who provide support to over 110,000 patients with advanced cancer yearly.</p>		
<p><b>2. Underpinning research</b> (indicative maximum 500 words)</p> <p><b>Burke's</b> research identified <b>quality of life</b> benefits spanning physical, psychosocial, and spiritual domains of well-being [2-5] as well as key <b>factors affecting participation</b> in physical activity (PA) at multiple levels of influence [1, 6] in palliative/hospice patients with progressive disease and advanced rectal cancer patients awaiting surgery. This research [1-6] underpinned the development, testing, and implementation of an innovative 'Move to Improve' toolkit, which has improved patients' functional mobility and understanding of PA, increased the delivery of PA in rehabilitative palliative cancer care by healthcare providers, and guided PA strategies and staff training at the organizational level.</p> <p><b>Burke's</b> work [2-5] has contributed to a growing evidence base that shows that PA interventions have important physical and psychosocial health benefits in palliative/hospice and advanced colorectal surgical cancer patients. Evidence from this work has shown that PA results in improvements in treatment-related and advanced disease related symptoms including fatigue, pain, physical functioning, depression, and anxiety [2-5]. This work has also demonstrated that hospital-based high-intensity interval training involving a peer-based approach has positive effects on quality of life of advanced rectal cancer patients prior to surgery [4, 5]. Importantly, this work showed that it was not simply exercise alone that resulted in improvements in quality of life, but how the exercise programmes were designed and delivered; for example, by offering supervised in-hospital exercise sessions to instil confidence and peer-based support to promote social well-being [5].</p> <p>Burke et al. [2, 3] examined outpatients' experiences of participating in hospice-based Tai Chi and found that patients experienced respite from the adverse psychological (e.g., worries about the future) and physical (e.g., physical discomfort) consequences of their disease. This work also identified key aspects (e.g., breath work, gentle movements, meditation in motion) of group-based</p>		

Tai Chi required for reaping health benefits and mitigating experiences of social death [2, 3]. Factors that encouraged hospice patients to participate in Tai Chi were also identified including tailored and supervised sessions, autonomy, perceived sense of safety, and social interaction. The results from this work showed that hospice-based mindful movement interventions such as Tai Chi are an important rehabilitative strategy that can help cancer patients self-manage distressing symptoms and improve quality of life.

Burke's work [1-3, 6] has also identified factors at multiple levels of influence that impacted on the uptake and maintenance of participation in PA among advanced rectal cancer [6] and hospice patients [1-3]. Factors identified spanned individual (e.g., apprehension about PA-induced harm), interpersonal (e.g., group-based PA with peers), physical environment (e.g., limited facilities and access), community (e.g., personalized approach), and policy (e.g., absence of a policy and guidance for PA provision) levels. The results from this work showed that PA interventions that target multiple factors simultaneously are effective at successfully promoting enjoyment of, and adherence to, PA interventions in patients with advanced disease. This work [1] also assessed healthcare professionals' current PA practices and identified a need to develop best practice recommendations and interventions to promote and integrate PA in routine rehabilitative palliative cancer care.

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

[1] Burke, S., Utley, A., Belchamber, C., & McDowall, L. (2020). Physical activity in hospice care: A social ecological perspective to inform policy and practice. *Research Quarterly in Exercise and Sport*, 28, 1-14.

[2] Bradshaw, A., Phoenix, C., & Burke, S. (2020). Living in the mo(ve)ment: Exploring hospice patients' experiences of participating in Tai Chi. *Psychology of Sport and Exercise*, 49, 101687.

[3] Bradshaw, A., Walker, L., Borgstrom, E., & Burke, S. Tai Chi as therapy for alleviating experiences of social death in people with advanced, incurable disease: An ethnographic study. *Qualitative Research in Sport, Exercise, and Health*, in press.

[4] Brunet, J., Burke, S.M., Grocott, M.P.W., West, M.A., Jack, S. (2017). The effects of exercise on pain, fatigue, insomnia, and health perceptions in patients with operable advanced stage rectal cancer prior to surgery: A pilot trial *BMC Cancer*, 17, 153.

[5] Burke, S. M., Brunet, J., Sabiston, C. M., Jack, S., Grocott, M., & West, M. (2013). Patients' perceptions of quality of life during active treatment for locally advanced rectal cancer: The importance of pre-operative exercise. *Supportive Care in Cancer*, 21, 3345-3353.

[6] Burke, S. M., Brunet, J., Jack, S., Grocott, M., & West, M. (2015). Exploring the meaning of adhering to a pre-surgical exercise program for patients with advanced rectal cancer: A phenomenological study. *Psychology of Sport and Exercise*, 16, 88-95.

#### Grants:

2013-2017: National Institute of Health Research (NIHR-RfPB) (CoI): A pilot study to investigate improvements in physical fitness and quality of life resulting from a 9 week structured responsive endurance training programme (SRETP) following neoadjuvant chemoradiotherapy prior to elective rectal cancer surgery. £249,763

2019-2020: Research England QR SPF (PI): Developing and implementing recommended best practices to inform policy on physical activity in palliative and hospice care. £28,000

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

Burke's research [1-6] involving palliative/hospice care and advanced colorectal surgical cancer patients has underpinned the development, evaluation and adoption of a 'Move to Improve' tool kit for promoting and embedding physical activity (PA) into rehabilitative palliative cancer care.

The toolkit consists of: (i) an Interactive Information Book for patients **[A]** and; (ii) a healthcare provider PA Manual for prescribing, monitoring, and designing/delivering PA in routine care **[B]**. Prior to the development of 'Move to Improve' there were no interactive tools or best practice recommendations specific to the promotion of PA in rehabilitative palliative cancer care in the UK. Burke has delivered 3 **workshops and training sessions** to Sue Ryder staff (N=28; nurses, physios, occupational therapists, Feb 27<sup>th</sup> 2020 and Dec 17<sup>th</sup> 2020) from 7 hospices in the UK (each of these hospices has a portfolio of 1500 case load per annum), 1 training session (Dec 17<sup>th</sup> 2020) with Macmillan staff (N=4; physios), and 1 workshop and 1 training session with staff (N=18; nurses, physios, consultants, rehabilitation therapists, Feb 13<sup>th</sup> 2020) from Dr. Sardjito General Hospital in Indonesia. The program of workshops and training was severely constrained by the Covid-19 pandemic. The sessions that were delivered increased healthcare providers' knowledge on how to deliver PA to advanced cancer patients in hospice, community, and hospital settings as well as how to use the toolkit **[C, D]**. During Burke's visit to Indonesia (Feb 9-16<sup>th</sup> 2020), she also engaged in **patient involvement activities** with advanced breast cancer patients to raise patient awareness of the benefits of physical activity and elicit views and opinions on the toolkit and any potential cultural issues.

Burke has **tested** the toolkit in clinical practice with advanced cancer patients from 7 Sue Ryder hospices **[D]**. Qualitative (e.g., interviews, brief notes) and quantitative (e.g., record logs) measures were used during 2020 to gather feasibility, acceptability, and early evidence of impact data **[E, F, G]**. 14 healthcare providers from 7 Sue Ryder hospices took part in the testing. This work was funded by a grant from Research England's Strategic Priorities Fund awarded to Burke. Testing of the toolkit resulted in: (i) an improvement in patients' functional mobility and understanding of PA; (ii) an increase in healthcare providers' knowledge and delivery of PA provision and; (iii) the development of PA strategies and staff training at the organizational level **[H]**.

#### Impact on patients' functional mobility and understanding of PA.

An evaluation of the interactive book **[A]** with patients showed a measureable increase in patients' functional mobility and overall understanding of PA. Healthcare providers reported improvements in patients' balance ability (e.g. one leg stand) and functional ability (e.g., walking):

*"One of our out-patient physiotherapists saw a patient who had heart disease, so he was in for heart failure, and she did it [used the patient book] with him and she got positive results from it. She said it was really good for improving the patients' functional mobility. When she first initially saw him on the 1<sup>st</sup> of December - when she initiated the programme [Move to Improve] - his single leg stand was 10 seconds and on the 24<sup>th</sup> which is just under a month later he was at 60 seconds. This improvement helped him to increase his walking distance." **[H]***

Patients found the interactive exercises (e.g., resistant band exercises) to be enjoyable. The exercises gave them confidence to safely engage in PA. Healthcare providers also reported that patients increased their knowledge and understanding of the types of activities they should be doing and how to overcome barriers. They reported improvements in patients' understanding of the psychological benefits of PA and how to incorporate activities into their day-to-day lives:

*"Quite often our patients want to do exercises but don't know how to incorporate it into their daily lives. One of the things that I particularly like about Move to Improve is that it really gives direction about how to incorporate exercise into patients' daily function. It is helping our patients better understand the benefits of physical activity and how to be more active." **[H]***

#### Impact on healthcare providers' knowledge and delivery of PA

Testing of the patient book **[A]** showed an increase in healthcare providers' delivery of PA in clinical practice. The patient book provided healthcare professionals with novel exercises that they incorporated into routine care:

*"I am regularly using two of the Move to Improve activities - activity # 3 chair leg raises and activity # 10 chair sit ups. And sometimes just bed exercises when standing from the bed is all the exercise that the patient is able to do. So because of this [Move to Improve] I am doing more functional exercises with our patients, which is quite good." [H]*

*The healthcare professional manual developed by Burke [B] led to an increase in healthcare providers' (n=46) knowledge of how to deliver PA when caring for advanced cancer patients who have limited functional mobility and complex, high dependency needs. Healthcare providers stated that the manual was a useful tool that helped them to feel more knowledgeable about how to counsel, prescribe, monitor, and promote active lifestyles when caring for patients. It has been cascaded to a wide range of allied health professionals (e.g., nurses, occupational therapists, physiotherapists) across Sue Ryder, as well as to Dr. Sardjito General Hospital who work within multidisciplinary teams to increase knowledge of PA as a rehabilitation strategy. These healthcare providers combined give support to over 10,000 patients receiving advanced cancer care on an annual basis.*

*"It [the health professional manual] is a very good resource that we have been sharing with our non-allied health professionals like our nursing assistants who work in the hospice, which has boosted their knowledge of the benefits of exercise and reinforced why we tell them it's important to incorporate physical activity into their day to day contact with patients." [H]*

*The patient book [A] was used as a resource to give to patients to support the care provided to patients by healthcare professionals:*

*"We don't have any literature that we give to our patients at all about physical activity. This [the patient book] really supports what I spend quite a lot of time encouraging patients to do and it's so nice to have something to give them." [H]*

The patient book was also reported as a useful tool that improved job satisfaction from seeing patients benefits from utilizing the book and participating in the exercises offered at the hospice/hospital. The manual was viewed as an important source of information for staff on how to safely and effectively promote PA in palliative rehabilitative cancer care [J].

#### Impact on rehabilitative care at the organizational level

The adoption of the toolkit [A, B] in 8 advanced cancer care establishments has changed the way palliative care organizations (i.e., Sue Ryder and Dr Sardjito General Hospital) deliver physical activity in rehabilitative care in numerous ways [I]. First, Sue Ryder has embedded 'Move to Improve' into staff nurse training, and the use of this is currently under review to become mandatory training for all their health professionals and incorporated into benchmarking and core competencies.

*"The manual for health professionals has been used, in some of our [Sue Ryder] hospices, as part of our staff nursing training and it is currently under review to become mandatory training for all our health professionals." Research Lead, Sue Ryder [D]*

Second, Sue Ryder has identified a PA champion at 6 of their hospices who is leading on the delivery and monitoring of physical activity in rehabilitation cancer care (and 4 hospices have created designated spaces within each hospice for the delivery of activity sessions). Third, both Sue Ryder and Dr. Sardjito General Hospital have recognized the importance of physical activity prescription and monitoring and have begun embedded best practice recommendations developed by Burke within their strategy:

*"Dr Burke's work is leading the way in the use of research within our services to benefit patients. Health and social care professionals at all 7 of our palliative care sites across the UK are using her physical activity manual and interactive information patient book...Dr Burke's work has acted as the catalyst to incorporate physical activity into our Sue Ryder strategy." Professional team lead for Education, Sue Ryder [I]*

Fourth, testing of the toolkit in clinical practice showed a measurable increase in the number of mindful movement (e.g., Tai Chi, yoga) and circuit sessions delivered to patients (at 5 out of the 7 Sue Ryder hospices). The toolkit was reported to have enabled clear and consistent guidance on the design and delivery of these sessions and facilitated good practice. Finally, the toolkit has been shared with Hospice UK and Macmillan who have begun working with Burke to develop PA recommendations to inform policy as well as host and promote materials online.

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

**[A]** Interactive Information Book (IIB) for patients (January 2020)

**[B]** Physical Activity Manual (PAM) for healthcare providers (January 2020)

**[C]** Letter from the Clinical Oncologist, Universitas Gadjah Mada/Dr Sardjito Hospital, Yogyakarta, Indonesia (letter dated 03/12/2020)

**[D]** Letter from the Research Lead, Sue Ryder (letter dated 10/12/2020)

**[E]** Sample - Physical activity record log (collected during 2020)

**[F]** Sample - Brief notes: Service user (patient views of "Move to Improve") (collected during 2020)

**[G]** Sample - Brief notes: Healthcare professional (collected during 2020)

**[H]** Qualitative results (i.e., themes, sub themes, and supporting quotes) from the testing of 'Move to Improve' in clinical practice (obtained during 2020)

**[I]** Letter from the Professional team lead for Education, Sue Ryder (letter dated 13/01/2021)

**[J]** Letter from physiotherapist, Sue Ryder (letter dated 20/12/2020)