

Supporting patients and caregivers towards better self-management of side effects

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I have no commercial disclosure

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Introducing lower-grade gliomas

- The most common malignant brain tumours are gliomas, which can be grade 2, 3, or 4, distinguished by their expected prognosis and resectability
- Lower-grade gliomas (LGG) account for approximately 15% of all gliomas, encompassing grade 2 astrocytoma and grade 2 or 3 oligodendroglioma
- People with LGG are typically diagnosed in their 30s and 40s, a crucial time in working and family lives
- A LGG diagnosis will eventually progress to a high-grade glioma, though people with LGG can continue to live for 5 to 15 years, depending on the subtype

People with LGG may live long-term with a ‘terminal’ diagnosis, including the effects of the condition and its treatment, which could impact their ability to recuperate and resume daily activities.

Introducing self-management

‘Self-management is the awareness and active participation by the person in their recovery, recuperation, and rehabilitation to minimise the consequences of treatment, promote survival, health and well-being’

- Social cognition theories suggest that self-management is underpinned by an individual’s self-efficacy (i.e. their belief in their ability to perform a behaviour)
- To self-manage, people need a set of skills (e.g. problem solving, action planning), which interventions seek to equip them with
- Self-management should not be the sole responsibility of the person with the diagnosis
- People require support from a network of healthcare professionals, family and friends

Practical examples of self-management



The value in self-management



Systematic Review

Characteristics and Components of Self-Management Interventions for Improving Quality of Life in Cancer Survivors: A Systematic Review

Ben Rimmer ^{1,2,*}, Morven C. Brown ^{1,2}, Tumi Sotire ², Fiona Beyer ², Iakov Bolnykh ³, Michelle Balla ³, Catherine Richmond ², Lizzie Dutton ^{1,2}, Sophie Williams ⁴, Vera Araújo-Soares ^{1,2,5}, Tracy Finch ⁶, Pamela Gallagher ⁷, Joanne Lewis ⁴, Richéal Burns ^{8,9} and Linda Sharp ^{1,2}

Take-home messages

1. Self-management interventions can improve quality of life and reduce healthcare utilisation in cancer survivors
2. None were developed for people with brain tumours, so existing interventions may not be entirely transferable to the tumour-specific challenges experienced by this population
3. New interventions can learn from the characteristics and components that have been associated with improvements

Rationale

- The potential need for long-term management of the impact of living with a LGG suggests that supported self-management is a worthwhile consideration
- There is a paucity of evidence concerning self-management in people with brain tumours, with minimal evidence specifically focused on people with LGG
- Important to identify and understand the need and potential for supported self-management in people with LGG
- Understanding these experiences will highlight whether people with LGG can benefit from a self-management intervention



Ways Ahead

Improving support for people with brain tumours

Aim: To understand the lived experiences of people with LGG and the potential for supported self-management, from multiple perspectives.



Open access

Protocol

BMJ Open Ways Ahead: developing a supported self-management programme for people living with low- and intermediate-grade gliomas - a protocol for a multi-method study

Ben Rimmer ¹, Lizzie Dutton,¹ Joanne Lewis,² Richéal Burns,³ Pamela Gallagher,⁴ Sophie Williams,² Vera Araujo-Soares,¹ Tracy Finch,⁵ Linda Sharp¹

Two systematic reviews

Three interview sets:

People with lower-grade gliomas (n=28)

Family-members (n=19)

Healthcare professionals (n=25)

Four co-design workshops and a survey

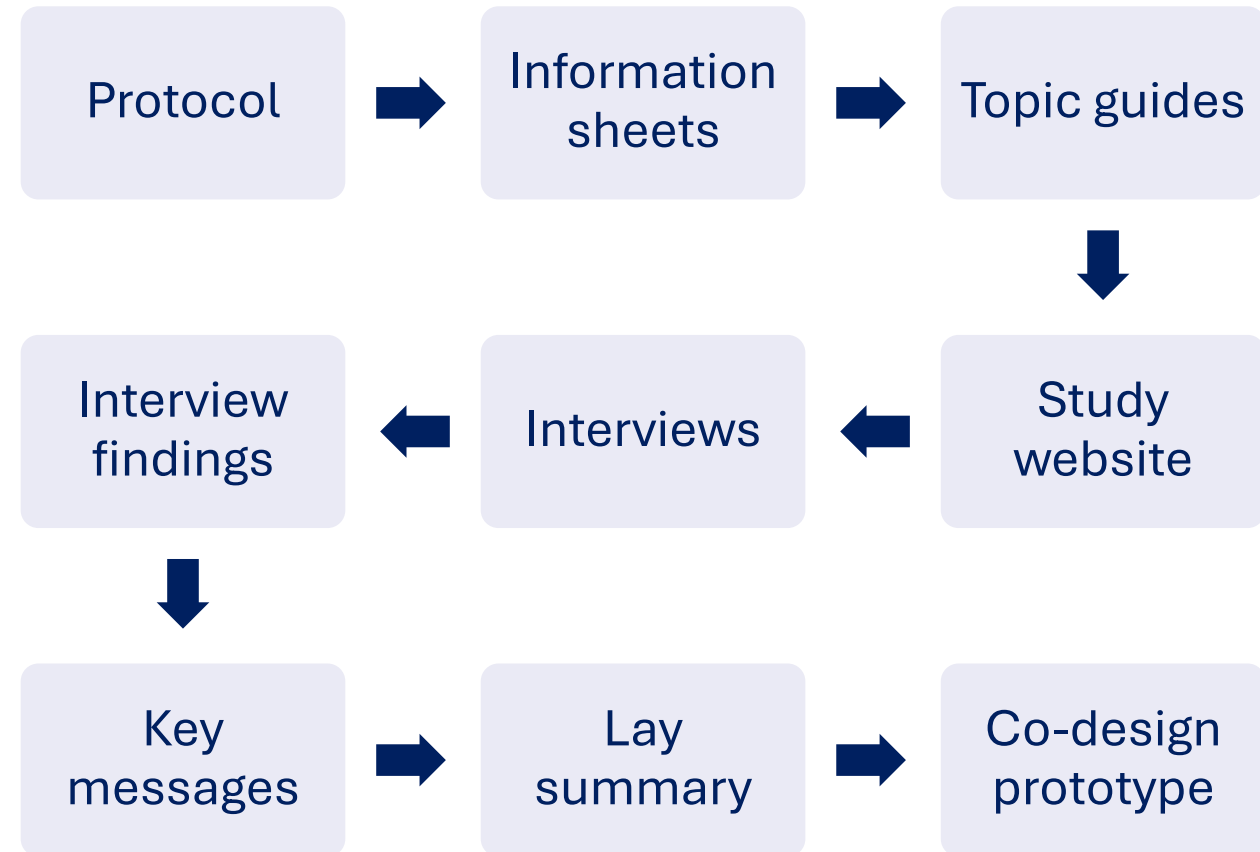
Patient and public involvement

Who? People with brain tumours and informal caregivers

Where? Brain Tumour Charity research involvement network and Maggie's Brains groups

What? Involvement across the design, analysis, and dissemination stages of the project

Why? To ensure the research was being conducted *with* the public, not *for* them



Study population

People with LGG

n=28

Mean age 50.4 years (range 22-69 years)

Male (n=16), Female (n=12)

Grade 2 oligodendroglioma (n=10), Grade 3 oligodendroglioma (n=9), Grade 2 astrocytoma (n=9)

Mean time since diagnosis 8.7 years (range 1-18 years)

Informal caregivers

n=19

Mean age 54.6 years (range 36-78 years)

Male (n=5), Female (n=14)

Wife (n=10), Husband (n=5), Mother (n=2), Sister (n=2)

Healthcare professionals

n=25

Mean time working with brain tumours 11.6 years (range 1-25 years)

12 different healthcare professions, such as Clinical Nurse Specialist (n=6), Occupational Therapist (n=4), Clinical Neuropsychologist (n=3), Physiotherapist (n=2)

Life with a lower-grade glioma

Quality of Life Research (2023) 32:625–651
<https://doi.org/10.1007/s11136-022-03207-x>

REVIEW

Health-related quality of life in adults with low-grade gliomas: a systematic review

Ben Rimmer¹ · Iakov Bolnykh² · Lizzie Dutton¹ · Joanne Lewis³ · Richéal Burns⁴ · Pamela Gallagher⁵ ·
Sophie Williams³ · Vera Araújo-Soares^{1,6} · Fiona Menger⁷ · Linda Sharp¹

Aim: To examine how health-related quality of life (HRQoL) is impacted in adults with a LGG, including which aspects are impacted; population comparisons; temporal trends; and influencing factors

Key finding

29 papers reporting 22 quantitative studies found that people with LGG have poor HRQoL and experience wide-ranging symptoms (e.g. fatigue, seizures) and impairments (e.g. cognitive impairment) that are sustained over time.

Take-home message

These findings help recognise potential support needs and inform the types and timings of support needed.

Link

These findings signify *what* and *when* HRQoL may be affected but do little to help understand *how* this is experienced in daily life.

Life with a lower-grade glioma

Neuro-Oncology Practice

11(3), 255–265, 2024 | <https://doi.org/10.1093/nop/npae006> | Advance Access date 29 January 2024

“It changes everything”: Understanding how people experience the impact of living with a lower-grade glioma

Ben Rimmer^{*}, Michelle Balla, Lizzie Dutton, Sophie Williams, Joanne Lewis^{*}, Pamela Gallagher, Tracy Finch, Richéal Burns, Vera Araújo-Soares, Fiona Menger, and Linda Sharp, on behalf of the Ways Ahead Study Team[†]

Interview set: People with LGG

Analysis strategy: Inductive thematic analysis

Aim: To explore how people experience the long-term impact of living with a LGG and understand how symptoms and impairments drive impacts on daily living

Key finding

People with LGG experience wide-ranging impacts on daily living (e.g. social activities, work, transport, relationships), due to their symptoms, impairments, and incurable condition.

Take-home message

Understanding how HRQoL is experienced and what it means to people with LGG can inform the development of personalised care plans, tailored to the individual.

Link

Wide-ranging HRQoL impacts on daily living indicate a need for self-management, yet possible support needs may hinder an individual’s capacity or willingness to engage in self-management.

Experiences of self-management

Journal of Cancer Survivorship
<https://doi.org/10.1007/s11764-023-01425-x>



Identifying and understanding how people living with a lower-grade glioma engage in self-management

Ben Rimmer¹ · Michelle Balla² · Lizzie Dutton¹ · Joanne Lewis³ · Morven C. Brown¹ · Richéal Burns^{4,5} · Pamela Gallagher⁶ · Sophie Williams³ · Vera Araújo-Soares^{1,7} · Tracy Finch⁸ · Fiona Menger⁹ · Linda Sharp¹ · on behalf of the Ways Ahead study team

Interview set: People with LGG

Analysis strategy: Directed content analysis

Aim: To identify and understand how people with LGG engage in the self-management of their condition

Key finding

People with LGG reported the use of 123 self-management strategies (e.g. accepting the tumour and its consequences) across 20 strategy types (e.g. meaning making).

Take-home message

People with LGG show willingness to self-manage, through a diverse and substantial range of self-management strategies, which corroborate the HRQoL impacts (e.g. using cognitive aids).

Link

Substantial variation in the number of self-management strategies reported by each participant (19 to 54), indicated a need to understand whether people with LGG face any barriers to self-management.

Experiences of self-management

Journal of Cancer Survivorship
<https://doi.org/10.1007/s11764-024-01572-9>



Barriers and facilitators to self-management in people living with a lower-grade glioma

Ben Rimmer¹ · Michelle Balla² · Lizzie Dutton¹ · Sophie Williams³ · Vera Araújo-Soares^{1,4} · Pamela Gallagher⁵ · Tracy Finch⁶ · Joanne Lewis³ · Richéal Burns^{7,8} · Fiona Menger⁹ · Linda Sharp¹ on behalf of the Ways Ahead study team

Interview set: People with LGG

Analysis strategy: Framework method

Aim: To identify and understand the barriers and facilitators to self-management in people with LGG

Key finding

People with LGG reported five categories (e.g. health status), encompassing 18 factors (e.g. cognitive functioning) influencing their ability to self-manage.

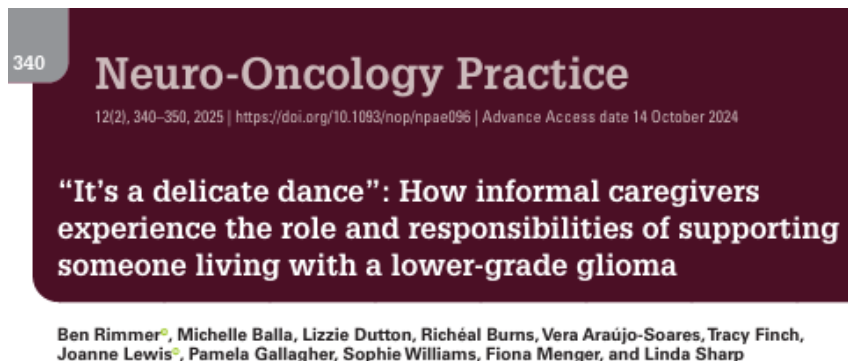
Take-home message

Understanding the multiple, often co-occurring challenges faced by people with LGG improves awareness of where support may be required to facilitate self-management.

Link

Access to informal support (e.g. from family) was a facilitator, whereas lack thereof, was a barrier to self-management. This indicated a need to understand the support role of close family and friends.

The role of informal caregivers



Interview set: Informal caregivers

Analysis strategy: Inductive thematic analysis

Aim: To identify and understand how informal caregivers experience the role and responsibilities of supporting someone with a LGG

Key finding

Informal caregivers reported providing wide-ranging support (e.g. emotional, practical, healthcare advocacy) to people with LGG to help them manage their condition.

Take-home message

Supporting informal caregivers to overcome caregiving challenges (e.g. conflict with work/childcare; lack of information) could help improve outcomes for people with LGG.

Link

Informal caregivers experience difficulty with providing support without inhibiting the care recipient's independence. This indicated a need for formal support to empower people with LGG and their family.

Self-management support in healthcare

DOI: 10.1111/hex.14073

ORIGINAL ARTICLE

WILEY

Understanding supported self-management for people living with a lower-grade glioma: Implementation considerations through the lens of normalisation process theory

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Vera Araújo-Soares PhD, Professor^{1,8} | Fiona Menger PhD, Lecturer⁹ |
Linda Sharp PhD, Professor¹ | Ways Ahead study team

Interview sets: Healthcare professionals; People with LGG

Analysis strategy: Framework method

Aim: To use the lens of normalisation process theory to identify and understand the considerations required to implement self-management support for people with LGG

Key finding

Evidence was generated for all four constructs (e.g. collective action) of normalisation process theory. There are wide-ranging considerations (e.g. how to identify support needs) required to operationalise, sustain, and appraise the feasible implementation of self-management support.

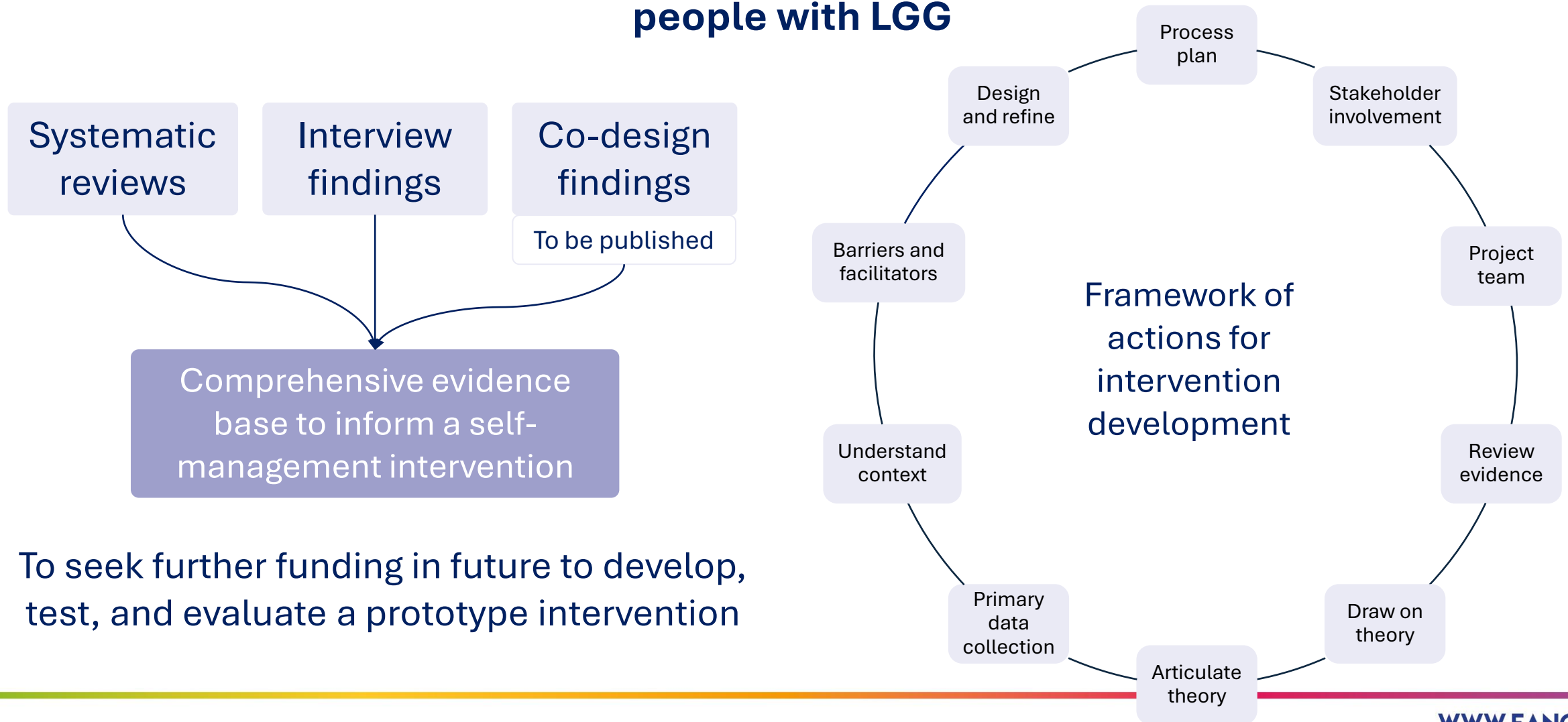
Take-home message

Supported self-management is a collective activity with important individual roles for people with LGG, informal caregivers, and healthcare professionals.

Link

This outlines the implementation potential of formal self-management support to empower people with LGG and their family.

Development of a self-management intervention for people with LGG



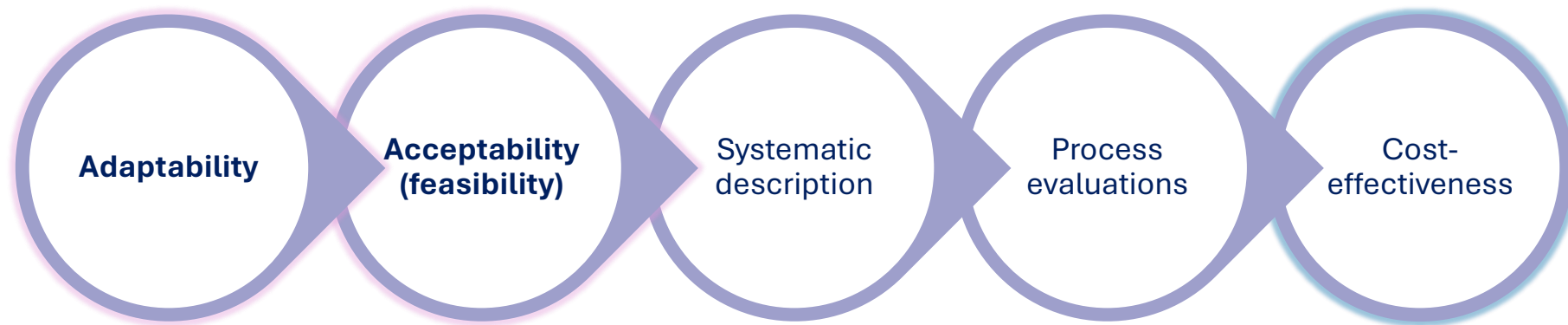
Implementation of self-management support for people with LGG in policy and practice

Journal of Cancer Education
<https://doi.org/10.1007/s13187-021-02021-2>

REFLECTIONS

Implementation of Self-Management Interventions in Cancer Survivors: Why Are We Not There Yet?

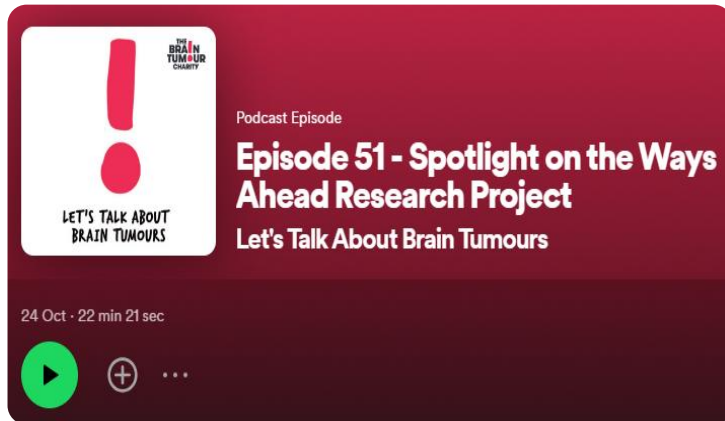
Ben Rimmer¹ · Linda Sharp¹ · on behalf of Ways Ahead study team



Overall take-home messages

1. This work provides novel and comprehensive understanding of the need, and potential for, supported self-management in people with LGG.
 - a. These insights could extend to other brain tumour types.
2. Involving multiple perspectives was valuable in capturing *how* and *why* people experience different roles and challenges in (supporting) self-management.
3. This work represents the groundwork for the development and implementation of self-management support, to improve the quality of life of people with brain tumours.

Thank you for listening



Ways Ahead researchers

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