MyMS-Ally: A Group Psychological Intervention for People with MS

A protocol of the feasibility and acceptability study of a novel group psychological therapy for people with MS

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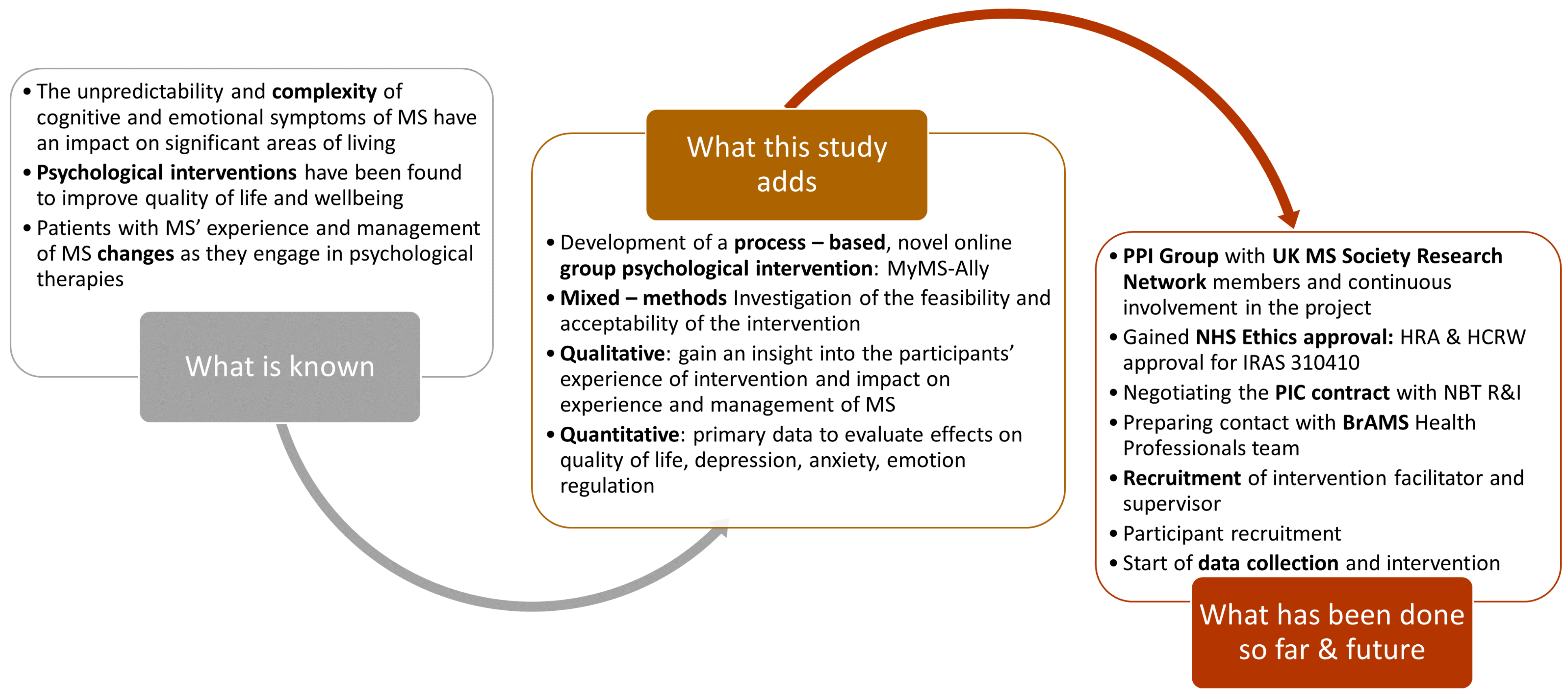
INTRODUCTION

Literature has focused extensively on the psychiatric and psychological dimensions of Multiple Sclerosis (MS) (Gay et al., 2017). People with MS have a higher prevalence of anxiety and depression than the general population (Marie et al., 2017). Developing a sense of coherence and control over their illness has been positively associated with people with MS's emotional, psychological and social wellbeing (Bassi et al., 2016; Calandri et al., 2018). The role of psychological interventions in these processes has been explored in previous research, and the results indicate how interventions such as Cognitive Behavioural Therapy, Mindfulness, and Acceptance and Commitment Therapy have moderate effects on fatigue, pain, resilience, positive affect, anxiety, depression and stress management (Simpson et al., 2019; Taylor et al., 2020).



What is known

- The unpredictability and **complexity** of cognitive and emotional symptoms of MS have an impact on significant areas of living
- **Psychological interventions** have been found to improve quality of life and wellbeing
- Patients with MS' experience and management of MS **changes** as they engage in psychological therapies

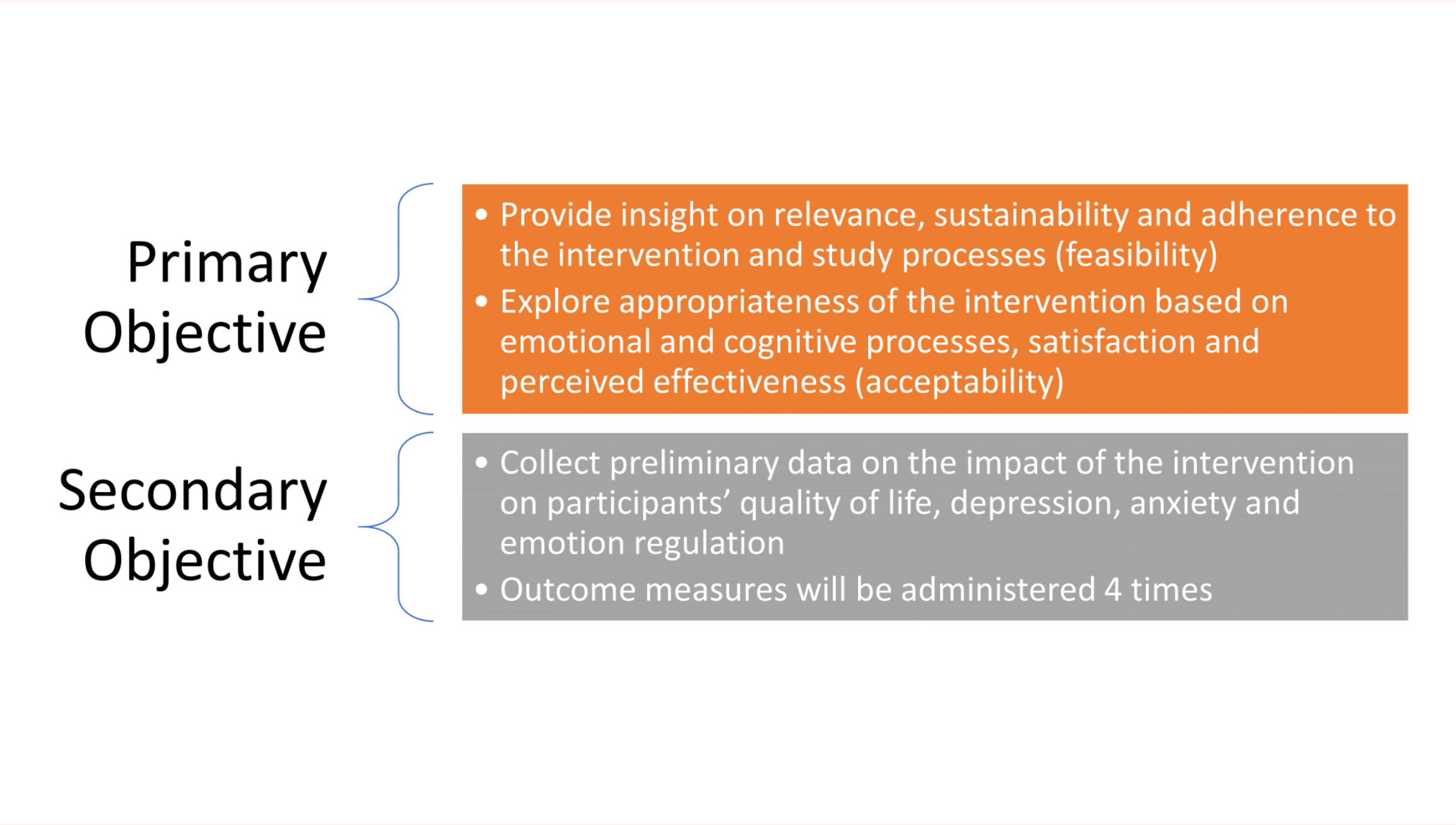
What this study adds

- Development of a **process – based**, novel online **group psychological intervention**: MyMS-Ally
- **Mixed – methods** Investigation of the feasibility and acceptability of the intervention
- **Qualitative**: gain an insight into the participants' experience of intervention and impact on experience and management of MS
- **Quantitative**: primary data to evaluate effects on quality of life, depression, anxiety, emotion regulation

What has been done so far & future

- **PPI Group** with **UK MS Society Research Network** members and continuous involvement in the project
- Gained **NHS Ethics approval:** HRA & HCRW approval for IRAS 310410
- Negotiating the **PIC contract** with NBT R&I
- Preparing contact with **BrAMS** Health Professionals team
- **Recruitment** of intervention facilitator and supervisor
- Participant recruitment
- Start of **data collection** and intervention

OBJECTIVES



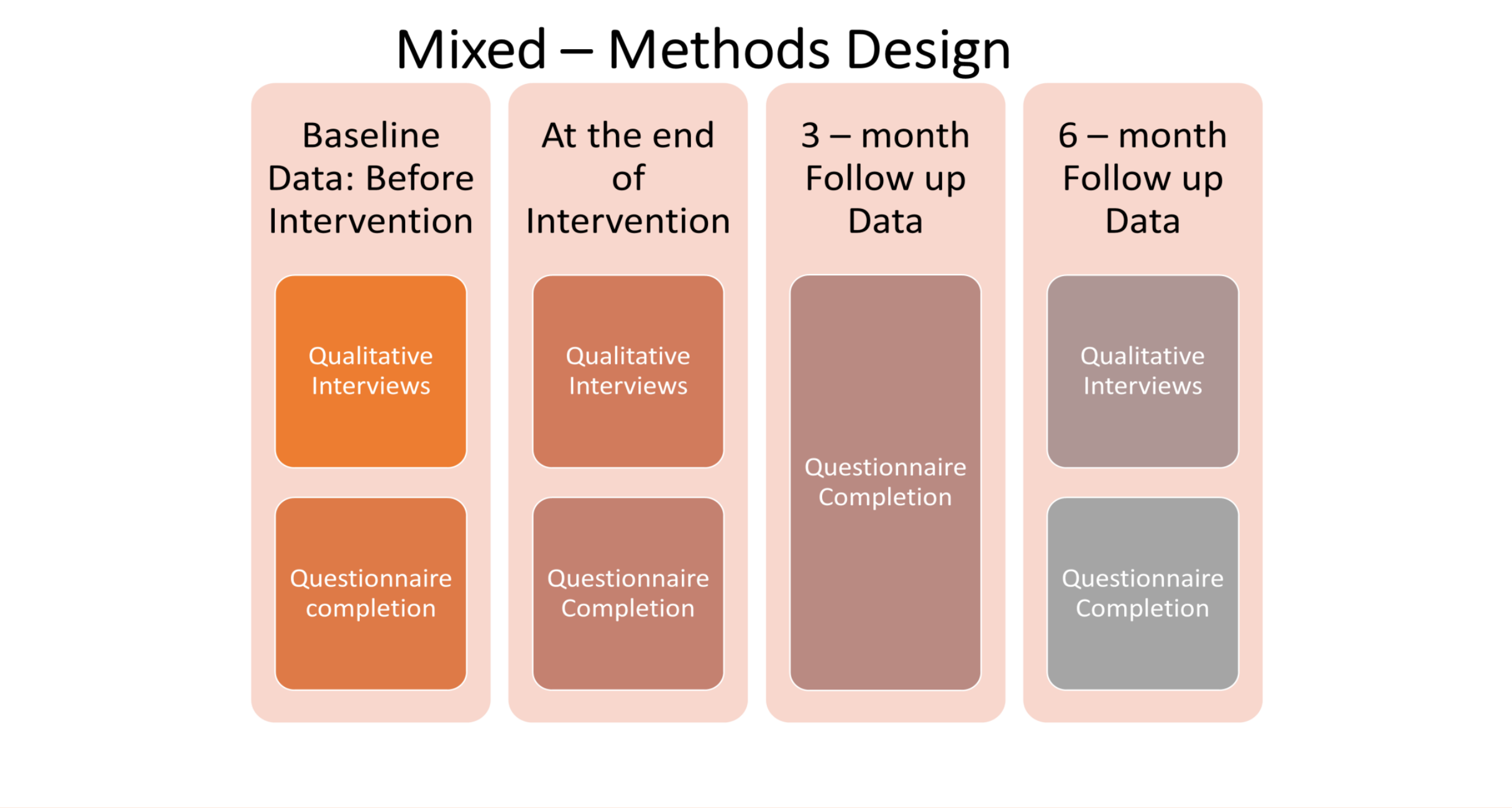
Primary Objective

- Provide insight on relevance, sustainability and adherence to the intervention and study processes (feasibility)
- Explore appropriateness of the intervention based on emotional and cognitive processes, satisfaction and perceived effectiveness (acceptability)

Secondary Objective

- Collect preliminary data on the impact of the intervention on participants' quality of life, depression, anxiety and emotion regulation
- Outcome measures will be administered 4 times

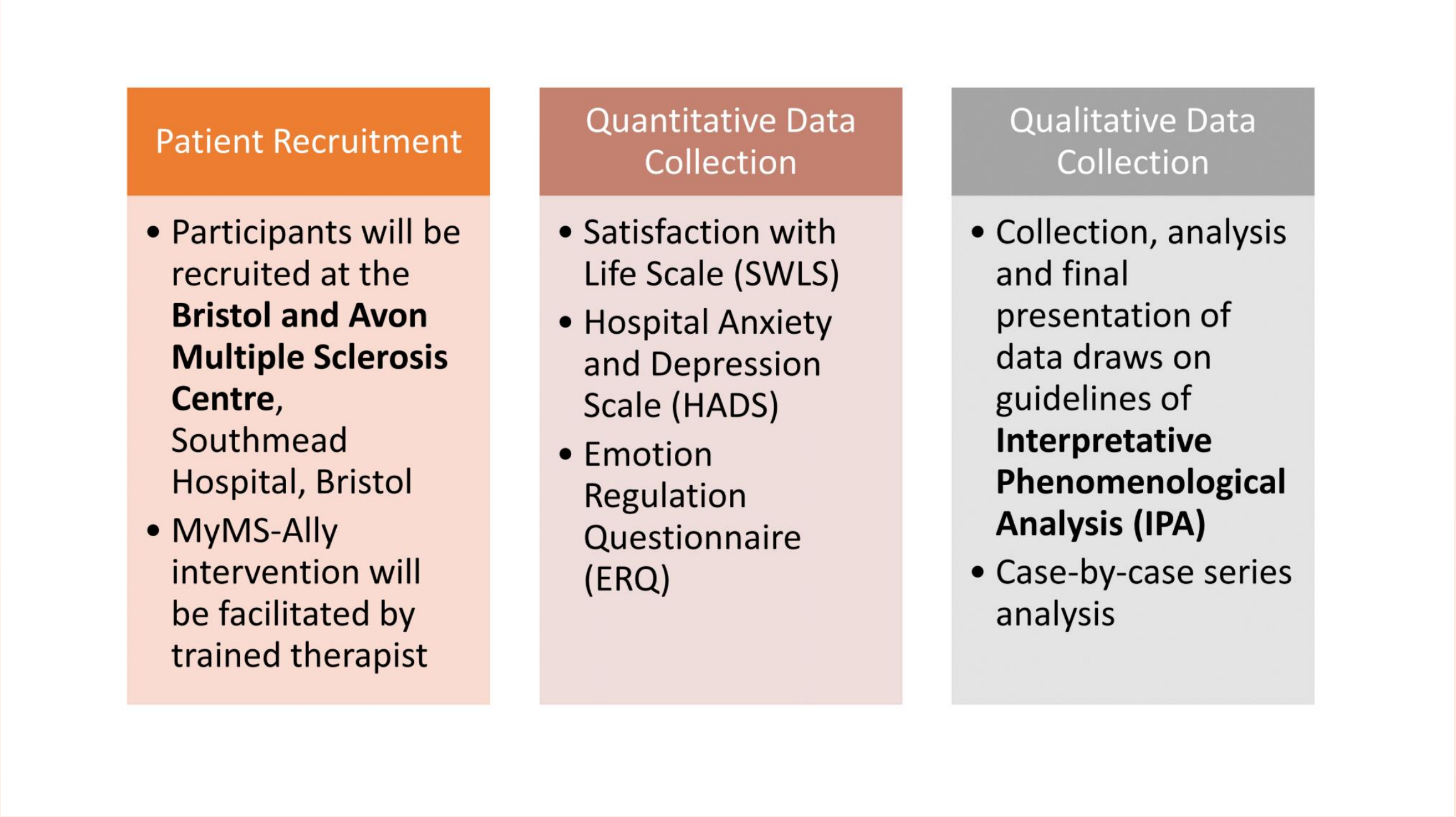
METHODOLOGY



Mixed – Methods Design

Baseline Data: Before Intervention	At the end of Intervention	3 – month Follow up Data	6 – month Follow up Data
Qualitative Interviews	Qualitative Interviews	Questionnaire Completion	Qualitative Interviews
Questionnaire completion	Questionnaire Completion		Questionnaire Completion

PROCESS



Patient Recruitment

- Participants will be recruited at the **Bristol and Avon Multiple Sclerosis Centre,** Southmead Hospital, Bristol
- MyMS-Ally intervention will be facilitated by trained therapist

Quantitative Data Collection

- Satisfaction with Life Scale (SWLS)
- Hospital Anxiety and Depression Scale (HADS)
- Emotion Regulation Questionnaire (ERQ)

Qualitative Data Collection

- Collection, analysis and final presentation of data draws on guidelines of **Interpretative Phenomenological Analysis (IPA)**
- Case-by-case series analysis

BEYOND GENERIC MODELS: DEVELOPMENT OF A PROCESS-BASED GROUP PSYCHOLOGICAL INTERVENTION

The generic models of psychological interventions that prevail in the literature cannot cover the complexity and the unpredictability of MS. Following the **process-based model**, psychological approaches can be developed based upon the specific characteristics and needs of people with MS. Their voices and preferences guided the development of MyMS-Ally group's psychological intervention, which has been developed based on previous research findings (Fragkiadaki et al., 2002), systematic reviews and meta–analyses, and consultation with practitioners. The MyMS-Ally group intervention will last for **two months,** and participants will be asked to attend **weekly sessions** that will last **1 ½ hours each** (8 sessions). The intervention will be conducted **online**. Following the **PPI** involvement focus group discussion, the group will comprise of **five to six participants**. It will also be ensured that the pace and the needs of the participants will be taken into account during the implementation of the intervention. For example, the facilitator will establish breaks during the sessions for the participants to take time and move away from their monitors. They will also incorporate overviews and summaries of previous sessions in the discussions.

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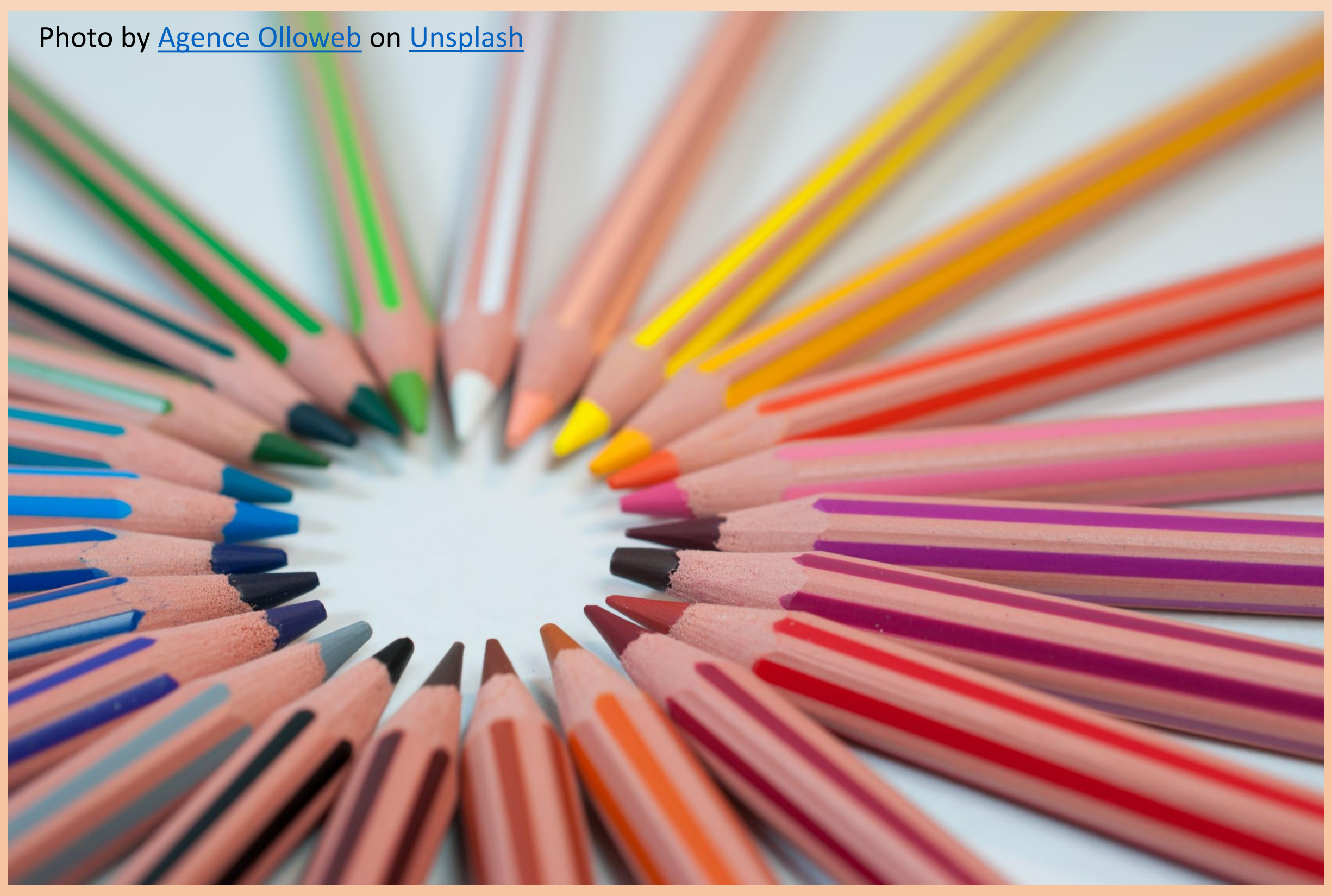

IDIOGRAPHIC METHODS OF EVALUATING INTERVENTIONS: TOWARDS A PATIENT – CENTRED APPROACH

The project adheres to an **idiographic** approach to exploring **processes of change** and the **impact** of the intervention (Haynes et al., 2009; Hofmann & Hayes, 2019). Previous research is mainly based on quantitative outcome measures and the findings present the effects of generic models on psychological and physical facets of MS. However, little is known about the **experiences of people with MS** that take part in these interventions, and especially about their needs and preferences with regards to psychological therapies involved in their care. The current study design offers the framework for statistically significant conclusions to be made. We also strive to incorporate **participants' meaning-making accounts** with an in-depth description of their experiences of the intervention. Each participant's variations and **changes over time** will be investigated through multiple points of data collection. Following the patient-centred regime, the aim of the researchers is to identify tailored evaluation processes that will eventually shed light on changes over time within each participant. Quantitative and qualitative methods are "compatible partners" in this research context (Onghema et al., 2019, p. 463) following a pragmatism epistemology combining action and reflection (Biesta 2010).

REFERENCES

1. Biesta, G. J. J. (2010). Pragmatism and the philosophical foundations of mixed methods research. In A. Tashakkori & C. Teddlie (Eds.), SAGE handbook of mixed methods in social & behavioral research (2nd ed., pp. 95-118). Thousand Oaks, CA: Sage.
2. Fragkiadaki, E., Anagnostopoulos, F. & Triliva, S. (2022). People with Multiple Sclerosis share their psychological therapy experiences: a mixed-method study towards a patient-centred approach to exploring processes of change. Sage Open, *(under review).*
3. Gay, M. C., Bungener, C., Thomas, S., Vrignaud, P., Thomas, P. W., Baker, R., ... & Montreuil, M. (2017). Anxiety, emotional processing and depression in people with multiple sclerosis. BMC neurology, 17(1), 1-10.
4. Haynes, S. N., Mumma, G. H., & Pinson, C. (2009). Idiographic assessment: Conceptual and psychometric foundations of individualized behavioral assessment. *Clinical Psychology Review*, *29*(2), 179–191. https://doi.org/10.1016/j.cpr.2008.12.003
5. Hofmann, S. G., & Hayes, S. C. (2019). The Future of Intervention Science: Process-Based Therapy. *Clinical Psychological Science*, *7*(1), 37–50. https://doi.org/10.1177/2167702618772296
6. Marrie, R. A., Walld, R., Bolton, J. M., Sareen, J., Walker, J. R., Patten, S. B., Singer, A., Lix, L. M., Hitchon, C. A., El-Gabalawy, R., Katz, A., Fisk, J. D., & Bernstein, C. N. (2017). Estimating annual prevalence of depression and anxiety disorder in multiple sclerosis using administrative data. BMC Research Notes, 10(1), 1–6. https://doi.org/10.1186/s13104-017-2958-1
7. Bassi, M., Grobberio, M., Negri, L., Cilia, S., Minacapelli, E., Niccolai, C., Pattini, M., Pietrolongo, E., Quartuccio, M. E., Viterbo, R. G., Allegri, B., Amato, M. P., Benin, M., De Luca, G., Falautano, M., Gasperini, C., Patti, F., Trojano, M., & Delle Fave, A. (2019). The Contribution of Illness Beliefs, Coping Strategies, and Social Support to Perceived Physical Health and Fatigue in Multiple Sclerosis. Journal of Clinical Psychology in Medical Settings, 28(1), 149–160. https://doi.org/10.1007/s10880-019-09692-6
8. Calandri, E., Graziano, F., Borghi, M., & Bonino, S. (2018). Depression, Positive and Negative Affect, Optimism and Health-Related Quality of Life in Recently Diagnosed Multiple Sclerosis Patients: The Role of Identity, Sense of Coherence, and Self-efficacy. Journal of Happiness Studies, 19(1), 277–295. https://doi.org/10.1007/s10902-016-9818-x
9. Simpson, R., Simpson, S., Ramparsad, N., Lawrence, M., Booth, J., & Mercer, S. W. (2019). Mindfulness-based interventions for mental well-being among people with multiple sclerosis: A systematic review and meta-analysis of randomised controlled trials. Journal of Neurology, Neurosurgery and Psychiatry, 90(9), 1051–1058. https://doi.org/10.1136/jnnp-2018-320165
10. Onghena, P., Maes, B., & Heyvaert, M. (2019). Mixed Methods Single Case Research: State of the Art and Future Directions. *Journal of Mixed Methods Research*, *13*(4), 461–480. https://doi.org/10.1177/1558689818789530
11. Taylor, P., Dorstyn, D. S., & Prior, E. (2020). Stress management interventions for multiple sclerosis: A meta-analysis of randomized controlled trials. Journal of Health Psychology, 25(2), 266–279. https://doi.org/10.1177/1359105319860185