

The Pelvic Flaw: Co-Producing Pelvic Health Physiotherapy with Women with Multiple Sclerosis (MS)

A Participatory Exploration of Pelvic Floor Dysfunction

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1. Background

More than 1 in 3 women are affected by one symptom of **pelvic floor dysfunction (PFD)**¹.

The **pelvic floor** is a group of muscles lining the bowel of the pelvis. They play an important role in bladder, bowel, and sexual health, contributing to our quality of life across our lifespan².

Childbirth, ageing and societal stigma mean that women face an increased risk of **PFD**². For individuals with **MS** (of whom women account for 2/3 of diagnoses)³, this risk is compounded by the disrupted neuronal communication between the brain/spinal cord and the pelvic floor muscles⁴.

- 50% of women with MS experience symptoms associated with bowel dysfunction⁵
- 80% of women with MS report bladder⁶ and sexual dysfunction⁷

Physiotherapy has the potential to improve pelvic floor function, increase confidence, self-esteem, and enhance quality of life⁸. However, for women with MS and PFD, current research is limited. Thus, NICE (2019) guidelines exclude women with MS from physiotherapeutic management, presenting a problem to provide evidenced based physiotherapeutic care⁹.

This project will be the first in the UK to use a participatory approach to co-produce knowledge with women with MS about their pelvic health needs. This will act as a catalyst to generate physiotherapy resources and/or therapies that are tailored to the needs of women with MS. Thus, the study was split into two project (Figure 1.).

The Aim:

Project 1: To explore the symptoms of PFD with women with MS, their experiences of pelvic healthcare, and seek solutions accordingly to their own healthcare priorities and therefore identify an action plan for improving pelvic health physiotherapy.

Project 2: To work together to implement the action plan from Project 1 for future pelvic healthcare development.

2. Methods

A pluralistic methodological approach - to improve patient health care, we should utilise the strengths of multiple perspectives. This study used qualitative participatory research methods through the lens of intersectional feminism.

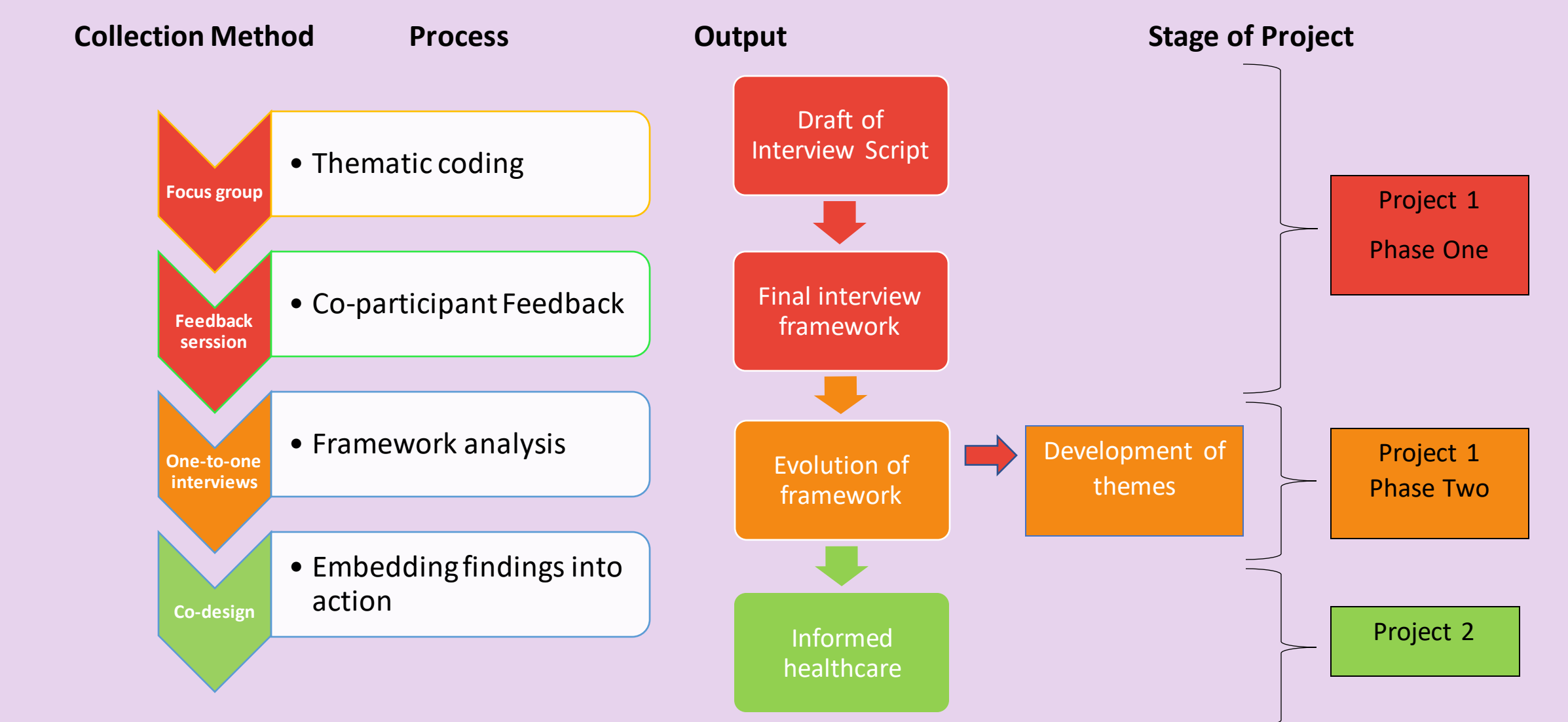


Figure 1. Schematic representation of study design and process.

Phase 1: Knowledge Gathering - virtual focus group to co-design interviews with women with MS.

Phase 2: Exploring Lived Experience - virtual one-to-one interviews.

Phase 3: Action Implementation - identify key areas for creating MS informed pelvic health.

Co-Participants

- Eleven women with MS participated in this project
- Four women took part in the focus groups
- Seven women took part in the one-to-one interviews.
- For both Phase One and Two inclusion criteria were; women 18 years of age and older, affected by MS with PFD issues, residing in the UK, and ability to understand co-participant requirements.

Analysis

1. Transcription
2. Familiarization
3. Coding
4. Development of tentative analytical framework
5. Application of framework
6. Charting data
7. Interpretation of data

3. Interpretation

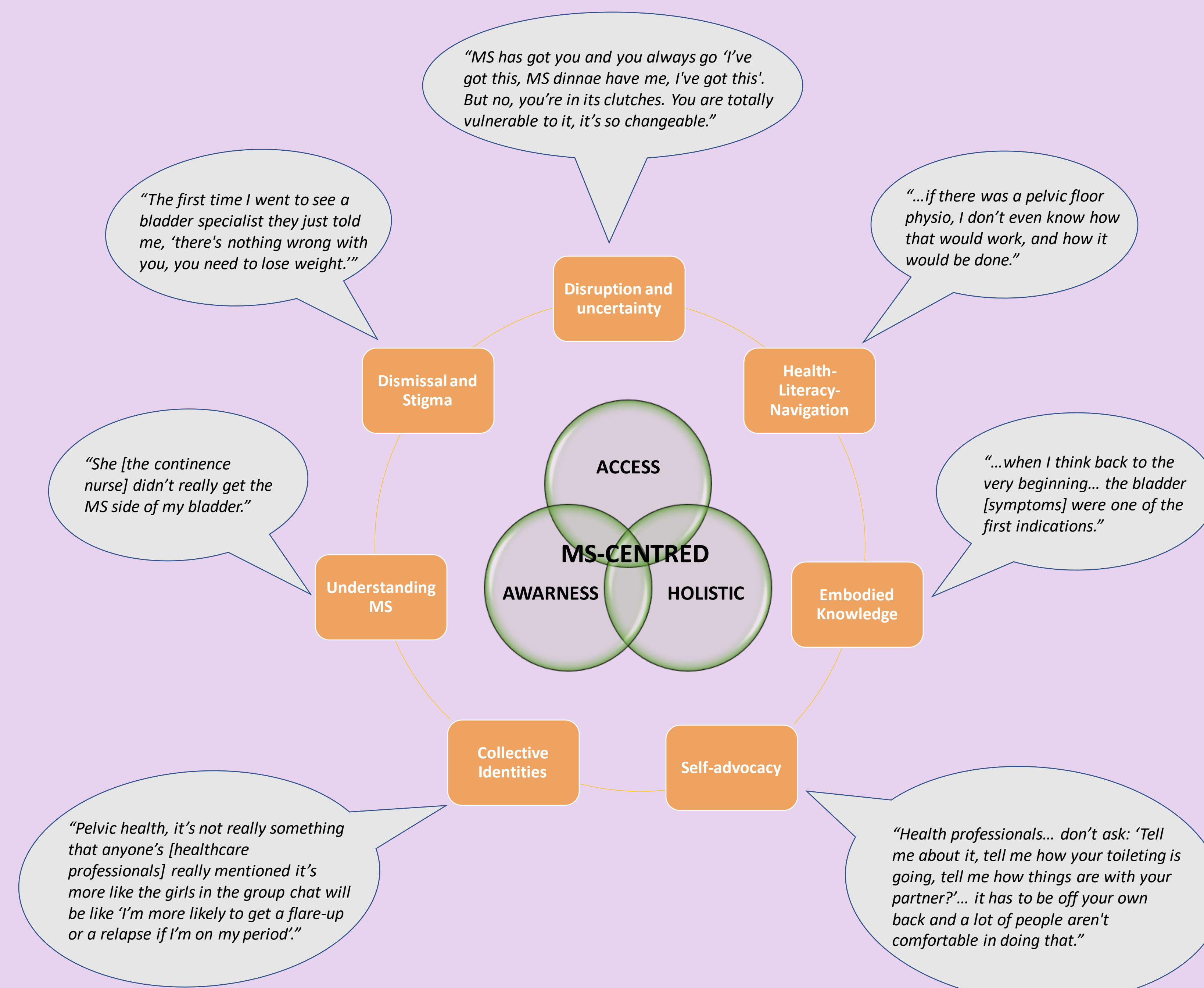


Figure 2. Schematic representation of findings.

The main themes derived from **thematic framework analysis** of these interviews included; disruption and uncertainty, health literacy navigation, dismissal and stigmatisation, the role of the MS nurse, self-advocacy, embodied knowledge, understanding MS and collective identities.

To implement these themes into an action plan for future service development, these themes were situated into **two domains**: The need for **holistic, MS-centred** pelvic health and wellbeing; The need to increase **awareness** and **access** to pelvic healthcare.

4. Discussion

Key points

Women with MS:

- Do not currently know what pelvic health physiotherapy services are available;
- Do not know how to approach seeking pelvic healthcare advice;
- Need specialist services that are holistic, and MS-centered;
- Services and clinicians need to show an understanding of the impact of MS on the individual; and
- Have experienced shame and dismissal from healthcare providers which prevent them seeking help.

These issues are unfortunately paradoxical to a recent study which found that MS specialist believe that it is the responsibility of the individual to discuss their pelvic health concerns¹⁰.

So, how can we place responsibility on the individual to access services if the system itself is difficult to access and navigate?

5. Implementation

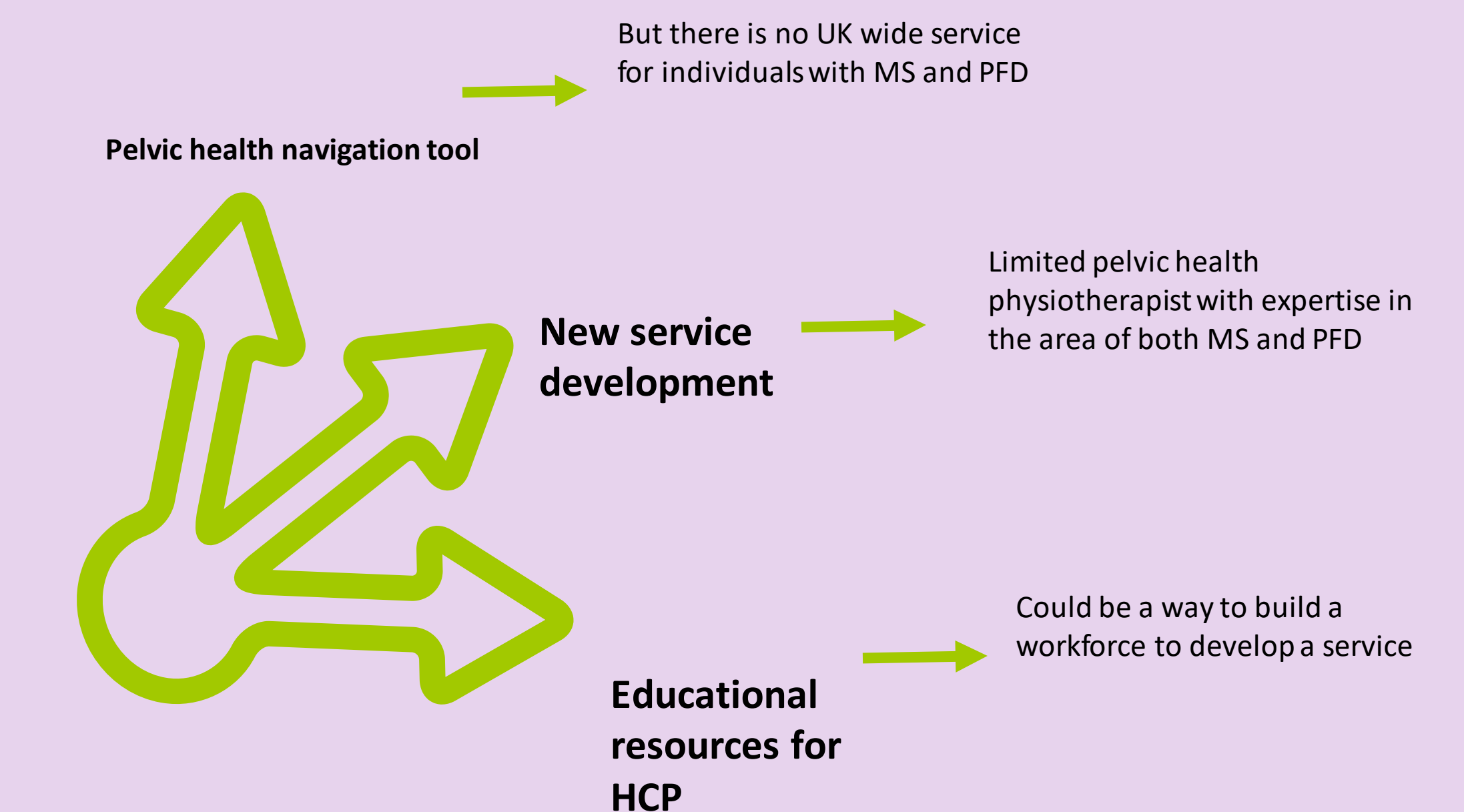


Figure 3. Map of potential solutions for implementing lived experience from project 1 into pelvic health physiotherapy.

In line with the UK Government's (2021) call for evidence to improve women's health, the Chartered Society of Physiotherapy (2021) has called for the government to improve access to pelvic healthcare, suggesting an increased number of specialist pelvic health physiotherapists and provision of funding to upskill more physiotherapy staff¹¹.

Project 2 will therefore look to co-design physiotherapy student pelvic health resources in collaboration with people with MS, healthcare professionals, educators and students. This will act as a foundation to have a workforce able to deliver tailor-made MS-centred services, from which a navigation tool can be developed.

References

1. LAWRENCE, J.M., LUKACZ, E.S., NAGER, C.W., HSU, J.Y. & LUBER, K.M., 2008. Prevalence and co-occurrence of pelvic floor disorders in community-dwelling women. *Obstetrics & Gynecology*, 111(3), pp.678-685. 2. Marques, A., Stothers, L., & Macraib, A. (2010). The status of pelvic floor muscle training for women. *Canadian Urological Association Journal = Journal De L'Association Des Urologues Du Canada*, 4(6), 419-424. doi:10.1007/s12191-010-9193-4. 3. Newsome, S. D., Alotta, P. J., Bainbridge, J., Bennett, S. E., Cutter, G., Fenton, K., et al. (2017). A framework of care in multiple sclerosis, part 2: Symptomatic care and beyond. *International Journal of MS Care*, 19(1), 42-56. doi:10.7224/1537-2073.2016-062 [doi]. 4. VITKOVA, M., ROSENBERGER, J., KROKAVCOVA, M., SZILASIOVA, J., GOOVINOVA, Z., GROOTHOFF, J.W. & VAN DIJK, J.P., 2014. Health-related quality of life in multiple sclerosis patients with bladder, bowel and sexual dysfunction. *Disability and Rehabilitation*, 36(12), pp.987-992. 5. MCCLURG, D., LOWE-STRONG, A. & ASHE, R., 2008. The benefits of pelvic floor muscle training in people with multiple sclerosis and lower urinary tract dysfunction. *Journal of the Association of Chartered Physiotherapists in Women's Health*, 10(3), pp.21-28. 6. ASHFAH, F., REZVANI, R. & ASHFAH, H., 2014. Sexual dysfunction in women with multiple sclerosis: Dimensions and contributory factors. *Journal of Research in Medical Sciences: The Official Journal of Isfahan University of Medical Sciences*, 19(3), pp.228-9. NICE. 2019. Guideline scope Pelvic floor dysfunction: prevention and non-surgical management. <https://www.nice.org.uk/guidance/pdf/section/10123/documents/fullscope> 11. Al Dandan, H. B., Galvin, R., McClurg, D., Coote, S., & Robinson, K. (2021). Management strategies for neurogenic lower urinary tract dysfunction: A qualitative study of the experiences of people with multiple sclerosis and healthcare professionals. *Nurs*, 1-11. doi:10.1080/09638288.2021.1887378by using qualitative participatory research methods through the lens of intersectional feminism.