

# Using an Evidence Café to investigate self-management behaviour in MS

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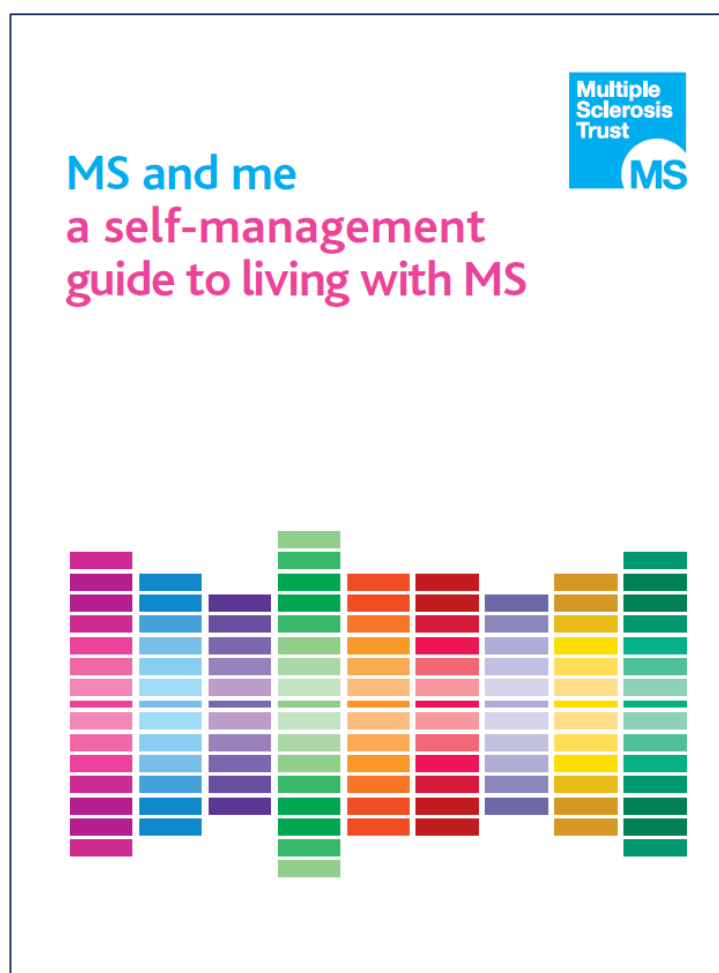
## What is an Evidence Café?

An Evidence Café is a special kind of focus group which encourages all stakeholder voices to be expressed. It uses structured discussion tasks to stimulate conversation and gather responses.

We gathered together a wide selection of people from the MS community:

MS nurses, therapists and neurologists; people with all kinds of MS and at different points in their journey; plus researchers, dieticians, exercise and digital technology experts.

34 delegates met at the Open University for a day of intense discussion.



## Why did we decide to hold an Evidence Café?

### MS and Me: a guide to self-management in MS

Like all our resources, this book went to peer and health professional readers as part of its 3-year review. Although it has been largely positively received, there were some key issues exposed by the reviewers:

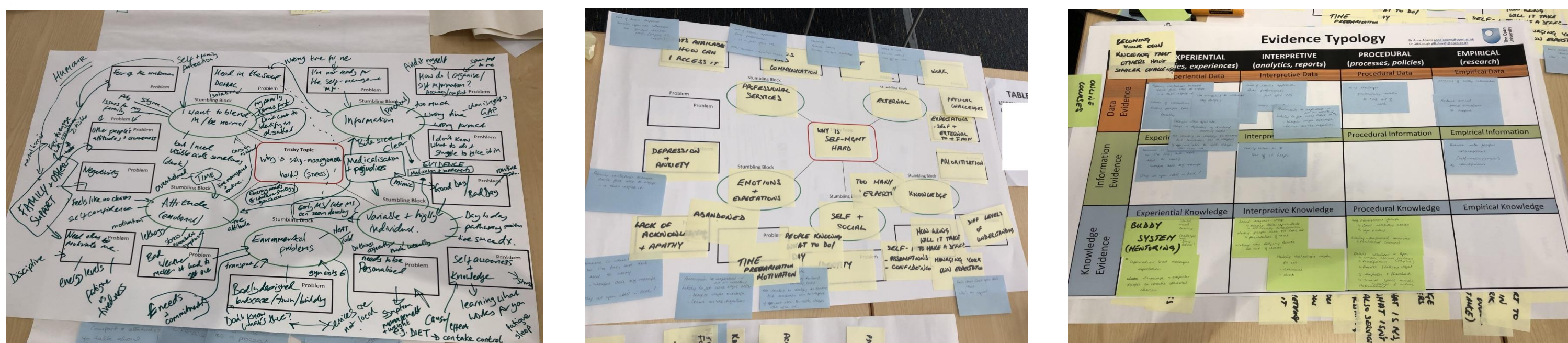
"It needs simple tools to help people make changes, not a raft of wishy-washy advice"

"Good general advice, but I didn't know where to start"

"I feel like I've failed if I can't stick to my plan"

"I start with good intentions, but have no-one to back me up"

"Reading the book, I bristled a little and felt judged"



## What were our questions?

Multiple sclerosis is a life-long condition. People with MS may see a health professional infrequently, but must manage their symptoms themselves for most of the time.

Although we say no-one should have to manage MS alone, how can we actually provide real help and support to people with MS?

What does self-management mean for people with MS?

Do people with MS know what they should do to live well with MS?

Why is self-management hard to do?

Is it realistic to expect one intervention to help everyone?

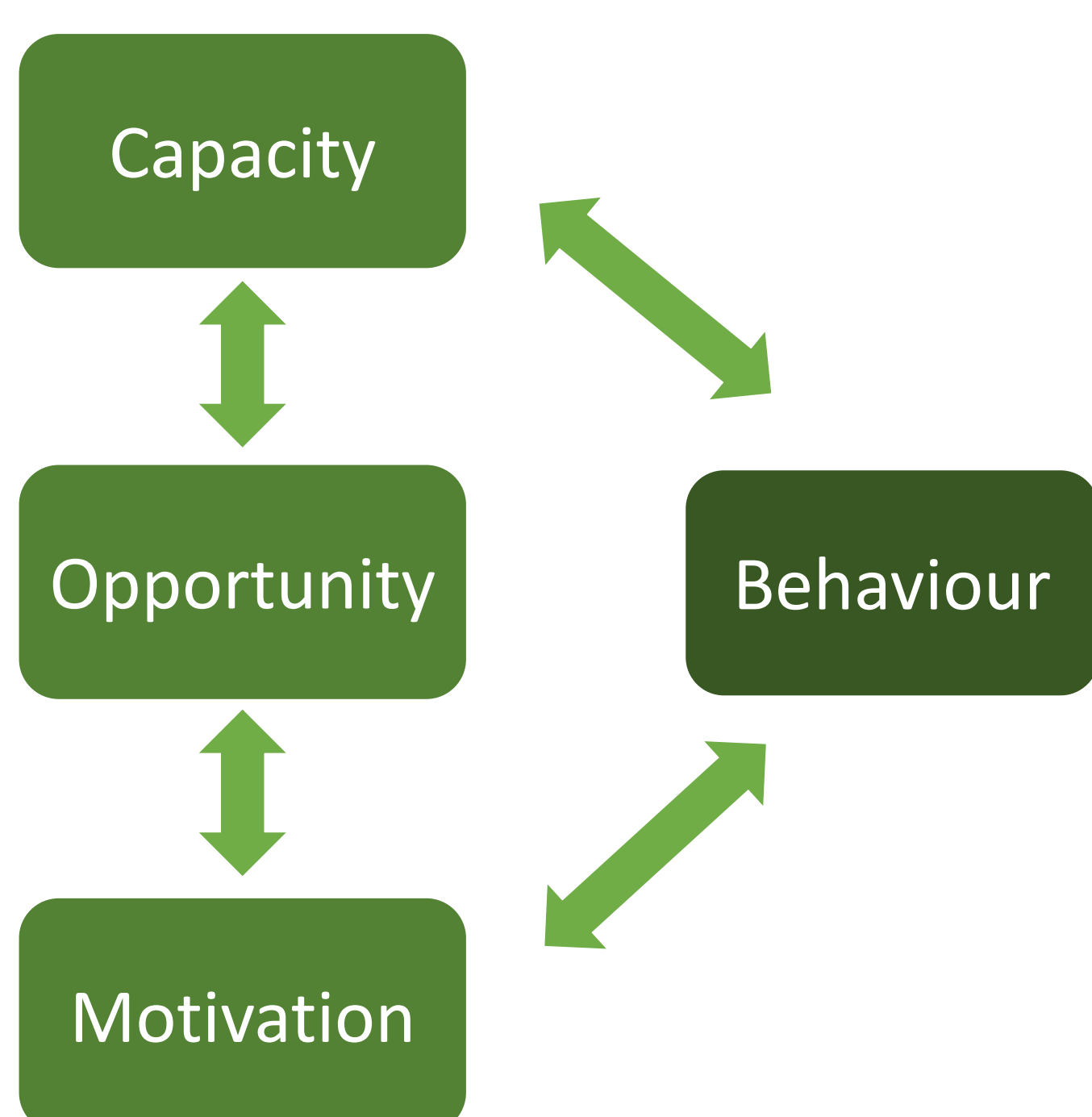
What would the best format for this resource be?

## What were the answers?

Evidence Café delegates agreed that our new resource should:

- ➔ Stress that self-management of MS succeeds best alongside good health care, where HPs work closely with the person with MS.
- ➔ Give people with MS clear information about what they can do to live well, and what behavioural changes will have most effect for them.
- ➔ Offer personally tailored information and support.
- ➔ Include support in monitoring progress and maintaining motivation.
- ➔ Give simple, specific and focused advice. One change at a time!
- ➔ Look at using local opportunities and peer support to overcome personal barriers to behavioural change.

## Behavioural Change Theory



The COM-B model explains why are some public health measures are effective while some are not.

We don't want to waste time and resources on something that won't work!

Using the Evidence Café data alongside the COM-B model helps us work out where the barriers to self-management are.

## What have we already done?

- Integrated practical self-management tips into all of our symptom management resources, such as the Living Well book series.

- Developed a series of smaller format publications for simpler, more direct information.

- Begun pilot work on a self-management course to be delivered via telephone and webinar.



## Conclusion

The Evidence Café format provided valuable insight into self-management behaviour and helped us identify what people with MS find difficult about it. This will lead to the production of self-management resources with greater impact and sensitivity.