

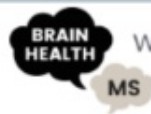
Digital Health & Patient Involvement in MS Research



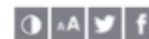
Sabina Brennan
PhD., C.Psychol., PsSI.

Solutions in search of a problem





Wake up to **Brain Health**



Search

Home

Brain

Health



Easy-to-understand information about brain health for people with MS



The **BRAIN** section serves up the basics on how your brain works, and how MS affects it.

Digital Trends

Knowledge



- knowledge mining
- natural language processing
- big data analysis
 - literature
 - clinical files
 - self-reports
- disease models
- digital diagnosis
- diagnosis support
- treatment

Digital Trends

Personalised medicine



- knowledge of you
- clinical history
- lifestyle
- behaviours
- dna
- tailor treatments
- more effectively

Digital Trends

Artificial Intelligence



- recruiting - clinical trials
- digital assistants

Digital Trends

Digital Assistants



- chat and dialogue systems
- digital diagnosis
- therapeutic routines
- Tele-med & remote evolve
- Ai supported services
 - research areas
 - voice interfaces
 - disease specific knowledge models

Digital Trends

Speech & Voice



- speech analysis to predict
 - health status
 - medical state
 - psychological state

Digital Trends

Virtual Reality



- digital diagnosis
 - TCD
 - pre-clinical dementia
- digital therapeutics
- Smart Camera+Speech tech
- Guide therapy programme

Digital Trends

Wearables



- internet of things
- reliable networks
- smart homes
- smart cities
- more data for
- crowd source
- detection
- management
- treatment

Digital Trends

Genetics



- gene editing
- dna testing
- awareness
- management

Digital Trends

Health Sensing



- everywhere
- IOT
- car
- multi-sensor fusion
 - predict
 - psychological
 - clinical state
- autonomous car





Passive Participants



Expert and Equal Collaborators



Patient Experts Add Value

Participants



Conceptualisation
Design
Delivery
Dissemination

Earlier the better
Embed from outset
Ongoing contact and collaboration





Mutual Respect

Symptoms
Side-effects
Transformative

Cure



Once Upon a Time...

Once upon a time © 2013

Disney Channel

A black and white photograph of a torn piece of paper. The paper is light-colored and has a rough, torn edge. The text "What's Important to You?" is written on the paper in a bold, black, sans-serif font. The paper is set against a dark, textured background. The lighting is soft, creating a slight shadow on the right side of the paper.

**What's
Important
to You?**

Effective
Efficient
Credible

BENEFITS

Quality & Relevance

- Accessible language & content
- Acceptable & sensitive methods
- Improved information for informed choices
- Meaningful applications

BENEFITS



Basic research - Blue Sky

- Correctly - not impede creativity
- Questioning & Conversation
- Enhance by encouraging
 - think outside the box
 - question why do things a certain way
 - think how to improve studies
 - challenge research
 - practices, attitudes, convictions

BENEFITS

Relevance

- address real patient issues
- focus on patient interests and concerns
- reshape and clarify research
- ideas for new research
- widen research topics
 - cure & treatment
- but also
 - empowering solutions
 - self-management
 - symptom management



BENEFITS

A hand holding a blue marker is shown underlining the word 'BENEFITS' in a large, blue, sans-serif font. The background is a light, blurred image of a person's arm and hand.

Patient & Research Benefit

- knowledge
- confidence
- satisfaction

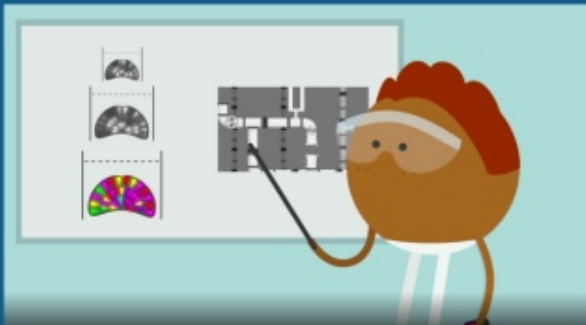
Patient Involvement in MS Research





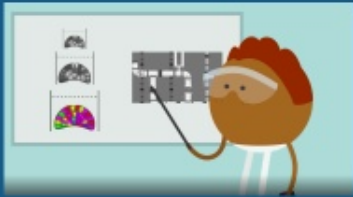
HOW DOES MS AFFECT MY BRAIN?

Research



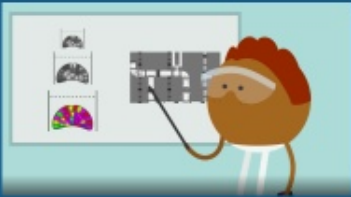
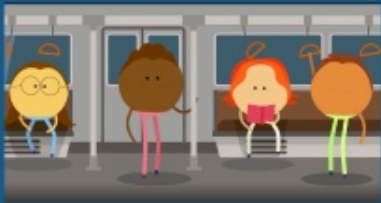
knowledge
reassurance
behaviour change
enjoyment

Findings



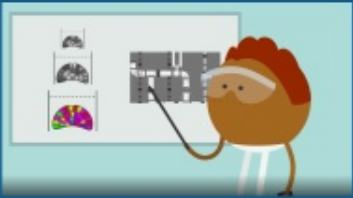
Knowledge
47% learned something new about MS
retained complex neuroscience
neurological reserve - 84%
brain health - 94%

Findings



Reassurance
significant reductions in fear
How does MS affect my brain?
How can I keep my brain health?

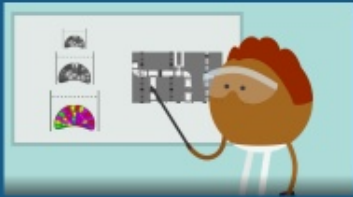
Findings



Behaviour

42% indicated intention to change behaviour

Findings



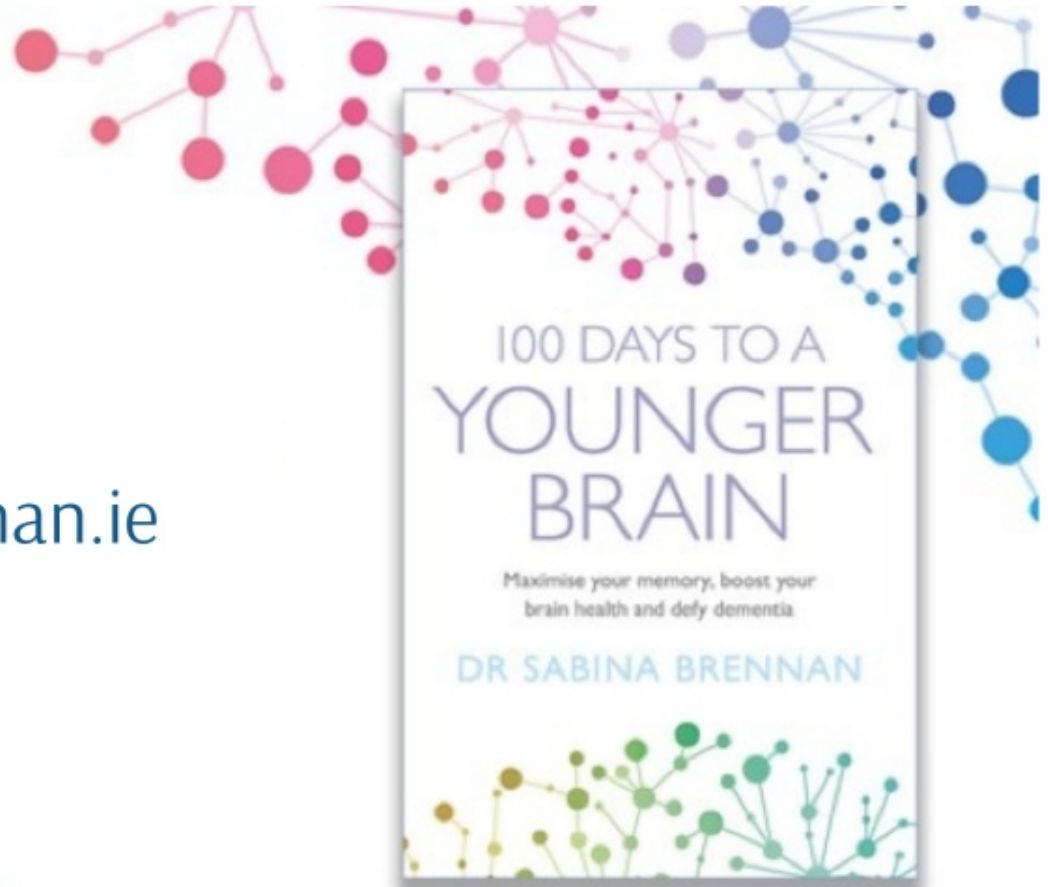
Enjoyable
Very enjoyable
Moderatel enjoyable



www.brainhealth4ms.com

Thank You

www.sabinabrennan.ie



@sabina_brennan

Digital Health & Patient Involvement in MS Research



Sabina Brennan
PhD., C.Psychol., PsSI.