Digital Health & Patient Involvement in MS Research

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Solutions in search of a problem
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

Artifical 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

Passive

Active

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...
What’s Important to You?
Effective
Efficient
Credible

Quality & Relevance
- Accessible language & content
- Acceptable & sensitive methods
- Improved information for informed choices
- Meaningful applications
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
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
Patient & Research Benefit

- knowledge
- confidence
- satisfaction
Patient Involvement in MS Research

- wider society
- outcomes
- public money
- public good
- priority setting
- across disease
- participation

Issues that matter and Real world applications
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
Moderately enjoyable
ACTIVITY          ATTITUDE          LIFESTYLE

GET PHYSICAL      KEEP SMILING     LOVE YOUR HEART

STAY SOCIAL      MANAGE STRESS    CHERISH SLEEP

GO MENTAL         BE PRESENT       CHOOSE BALANCE

www.brainhealth4ms.com
Thank You

www.sabinabrennan.ie

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