

“They’re getting a taste of our world”

A qualitative study of people with multiple sclerosis’
experiences during the COVID-19 pandemic in the Australian
Capital Territory.



Janet Drew

Health Experience Team

Our Health in Our Hands Program

Australian National University

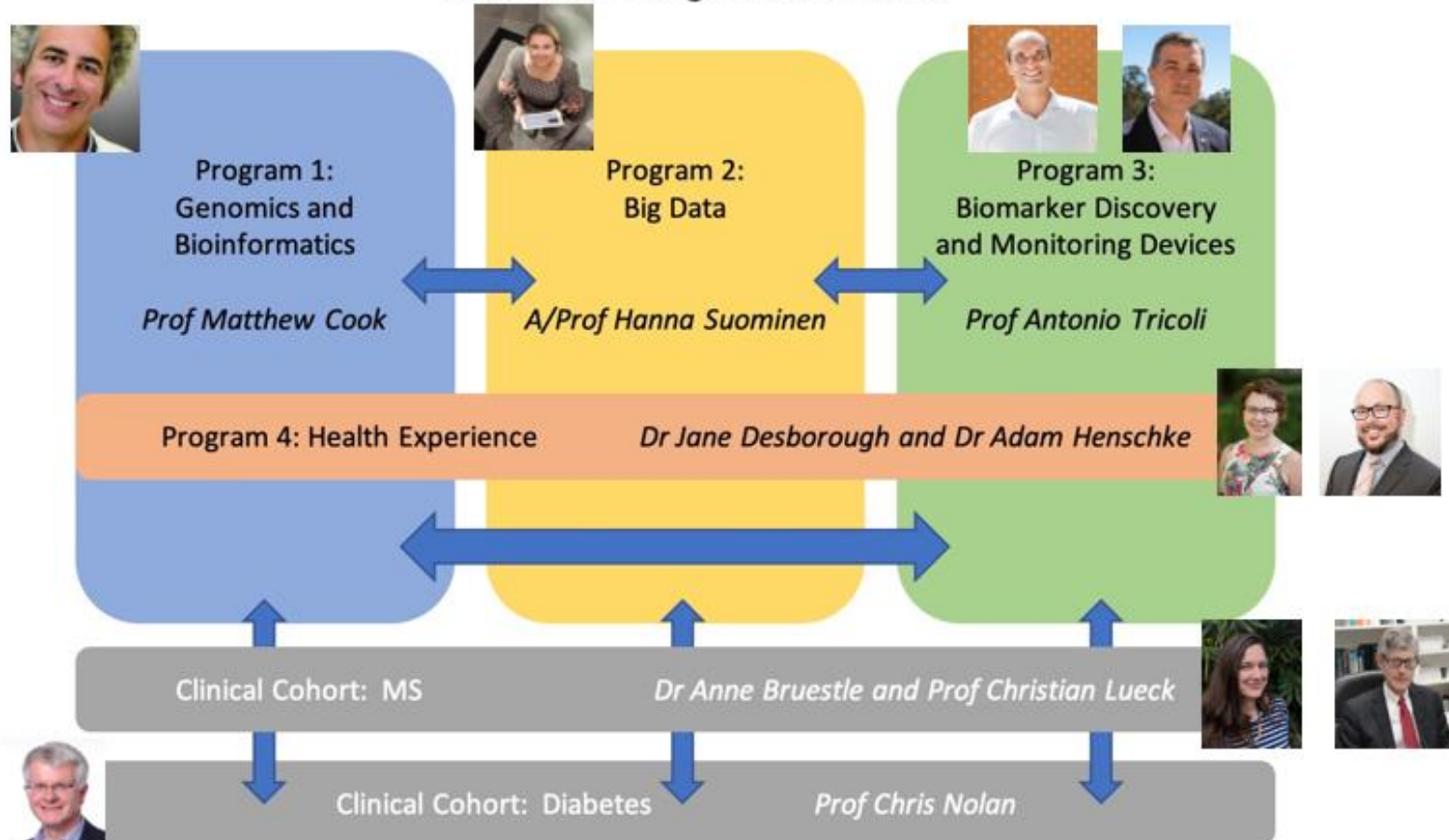
MS Symposium 2021 



Australian
National
University

Our Health in Our Hands (OHIOH)

Research Program Overview



Call it what you want it's all about collaboration and respect

Research conducted
'**with**' or '**by**' members
of the public rather
than '**to**', '**about**' or
'**for**' them

INVOLVE – What is public involvement in research?
<https://www.hra.nhs.uk/planning-and-improving-research/best-practice/public-involvement/> (accessed March 2021)

- Patient and public involvement (PPI)
- Consumer and community involvement (CCE)
- Co-creation
- Co-production
- Public participation
- Patient engagement



MS Health Experience Team



Back: Dr Anne Parkinson, Ms Danielle Squire, Ms Helena Paul, Mr Jack Leayr, Prof Christine Phillips, Dr Vanessa Fanning, Ms Janet Drew, Mr Mark Elisha.

Front: Dr Anne Bruestle, Assoc Prof Hanna Suominen, Dr Jane Desborough, Ms Katrina Chisholm



Aims and Method

To examine the experiences of people with MS in accessing health care during the COVID-19 pandemic in Australia

Qualitative descriptive approach

Semi-structured interviews

Thematic analysis
(Braun and Clarke)



Recruitment and participant characteristics

ID no.	Age (y)	Gender	Type of MS	Year of diagnosis	Disease-modifying therapy (DMT)	Choice of interview mode	Mobility
1	30-39	F	RRMS	2014	Glatiramer acetate	Online video	Active and able
2	30-39	F	RRMS	2017	Ocrelizumab	Telephone	Active and able
3	40-49	M	RRMS	2013	Natalizumab	Online video	Active and able
4	50-59	M	SPMS	1993	None	Online video	Requires mobility aid
5	20-29	F	RRMS	2012	Fingolimod	Telephone	Requires mobility aid
6	50-59	F	SPMS	2001	Glatiramer acetate	Telephone	Requires mobility aid
7	30-39	F	RRMS	2018	Ocrelizumab	Telephone	Active and able
8	50-59	F	RRMS	2009	None	Telephone	Active and able

Note: Requires mobility aid (chair and/or walking sticks).

Abbreviations: RRMS, relapsing-remitting MS; SPMS, secondary progressive MS.



Summary of consultations attended March-July 2020

Health-care professional consulted and modality	Participant ID							
	#1	#2	#3	#4	#5	#6	#7	#8
GP face-to-face	✓	✓	✓	✓	✓	—	✓	✓
GP telehealth via telephone	—	—	—	—	—	✓	✓	✓
GP telehealth via video	—	—	—	—	—	—	—	—
MS nurse telehealth via telephone	—	✓	—	—	—	—	—	—
AHCP face-to-face	—	—	✓	✓	—	✓	✓	✓
AHCP home visit	—	—	—	—	—	✓	—	✓
AHCP telehealth via telephone	—	—	✓	—	✓	—	—	—
AHCP telehealth via video	—	—	—	—	✓	✓	—	—
Neurologist face-to-face	—	—	—	—	—	—	✓	—
Neurologist telehealth via telephone	—	—	—	—	—	✓	—	—
Neurologist telehealth via video	—	—	✓	✓	—	—	—	—
Hospital services face-to-face (including magnetic resonance imaging (MRI), clinic visit and initial <i>Hospital in the Home</i> consult)	—	—	—	✓	—	✓	✓	—
<i>Hospital in the Home</i> visit to patient's home; face-to-face	—	—	—	✓	—	—	—	—
Other specialist telehealth via video	—	—	—	—	✓	—	—	—

Abbreviations: AHCP, allied health-care providers; GP, general practitioner (including psychologists, neuropsychologists, physiotherapists, exercise physiologists and massage therapists)



Theme 1

Assessing personal risk

“[W]ith this pandemic, everyone’s getting a bit of a taste of what it’s like to [have MS], like, you know, everyone’s talking about health. And that’s not really any different for us, They’re getting a bit of a taste of our world in some respects.” (#P2)

“I’m more of a germaphobe than I was before... [I] wouldn’t go out at all and my partner [does] the shopping and gets the mail and stuff like that because I [have] sort of refused to go anywhere.” (#P5)

“ I think we’ve got to be aware...Alert but not alarmed or something like that.” (#4)



Theme 2

Postponing usual care

I waited because I just wasn't comfortable going out in the early stages [of COVID] ... to see any health providers during the time time... [E]ven, like, mental health wise, I didn't have the mental energy to do anything about it [my mental health].

“[I]t’s an MS-type thing: you don’t freak out every time you have a bit of numbness or tingling and thinking that it’s a full-on relapse. It’s just something you’ve got to ride out and it’ll probably go away in due time.” (#P2)

I, like, didn't [get my MRI] because it seems like a really bad time to go out and get an MRI.” (#P1)



Theme 3

New ways of accessing care

“I must say it was better going in to see him [GP]... Although, when I'm on the phone, I can sort of have a list in front of me and work through it” (#P7)

“It's a lot more convenient just because I live quite a bit out of town to just do it on my phone.” (#P5)

“For a practitioner I hadn't consulted before I would like a video consult. [You] can learn more from seeing the person in real life and get a better understanding and appreciation of them.” (#P8)”

“I think telehealth is a really great initiative... [Implementing] new protocols and new ways of doing things has certainly been very positive...[I] would be really keen to utilise telehealth... [i]n the future, when appropriate, and for different things.” (#P2”)



Key messages

Participants felt telehealth was suitable for many, but not all, consultations and would consider incorporating telehealth consultations into their future usual health care routine where appropriate.

Personal risk assessment and trust in clinicians key

Video may have value for PwMS

Need for training and support for clinicians



Acknowledgement

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For further information about the OHIOH project, see <https://www.anu.edu.au/research/research-initiatives/our-health-in-our-hands>

Publication

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