



# Talk 6. “Have your say in healthcare – ways you can make your voice heard”

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**Jagdish Brar-Orgill – PPIE- Health & Social Care research**

**John Haddow – Patient Participation Group – Primary care**

**Ros Weinberg – Service User – Advocate**





# What we're discussing today

- Introductions
- The five ways to make your voice heard
  1. **the GP level** – where you can join the Patient Representation Group (PPG)
  2. **The secondary care level** (hospitals) – the Patient Advice and Liaison Service (PALS)
  3. Through **third party organisations** e.g. Healthwatch, the Patients Association, advocacy organisations
  4. **Health research route** – Get involved in ‘public patient involvement and engagement’ PPI / PPIE
  5. **The political path** - set up a petition to achieve ‘change’; speak to your MP





# Ros Weinberg

- Service user and self-advocate
- Manages type 2 diabetes with technology
- Member of PurpleSTARS
- Co-chair of the learning disability partnership board Redbridge
- Co-researcher at Rix Inclusive Research





# Who didn't have a bad experience at some point in their life when attending a health service?

What do we do about it? What can we do?

Why is it important to make your voice / your experience heard?

What can we influence?



# GP Level – John Haddow



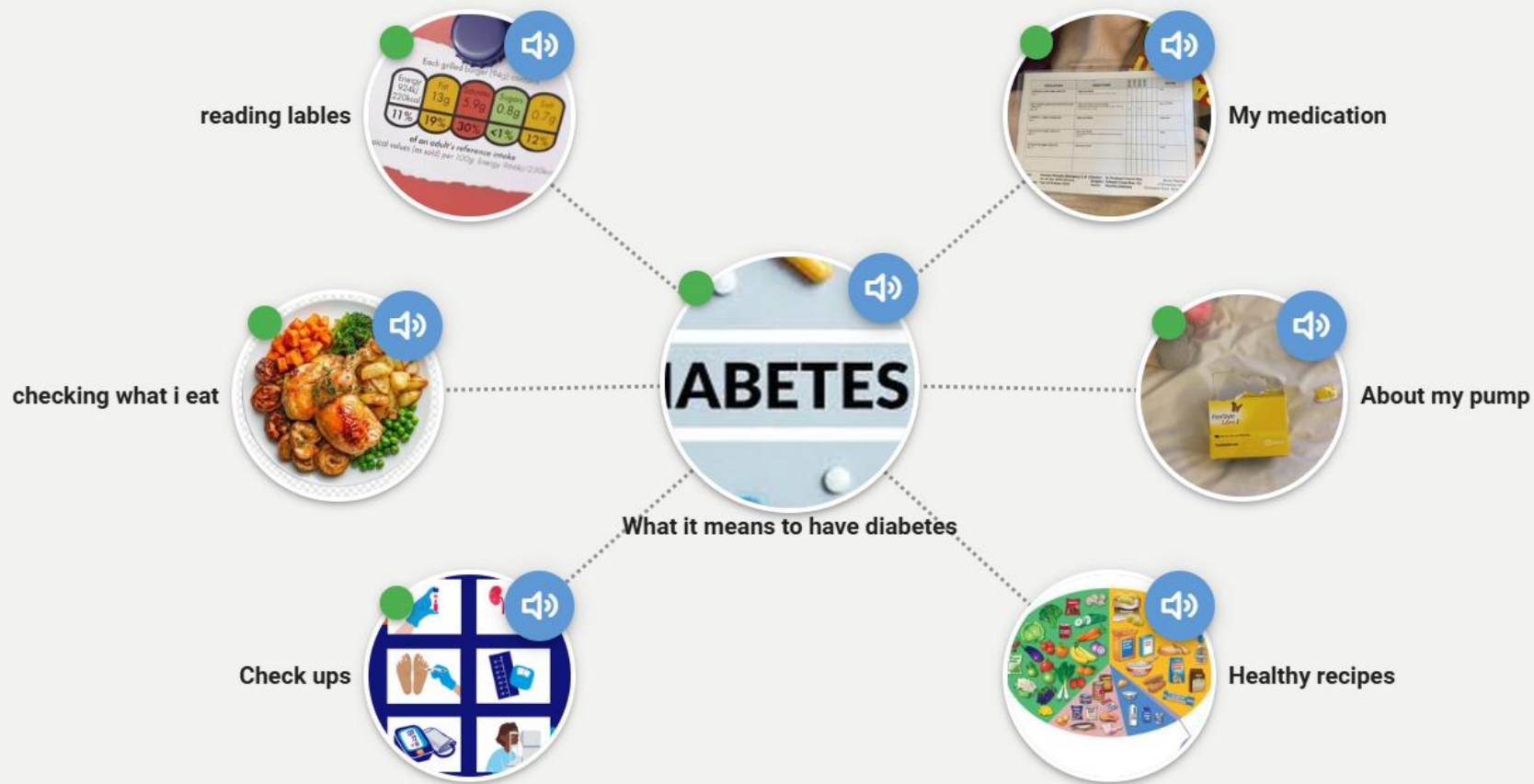














The purpose of the ADAPT study was to create an online toolkit of culturally appropriate assessments and interventions that support people from South Asian communities across the dementia care pathway



# SO...

## We created the ADAPT toolkit



<https://raceequalityfoundation.org.uk/adapt/>

A screenshot of the ADAPT website homepage. The header includes the ADAPT logo (South Asian Dementia Pathway) and navigation links for Home, The toolkit, About us, and Contact us. The main content area features the text: "An online toolkit of enhanced interventions" and "Overview of the issue". Below this, a paragraph states: "Roughly 25,000 people from ethnic minority communities live with dementia in the UK. The largest single grouping are people whose origins are South Asian countries. People from these communities are at greater risk of developing dementia. However, they are less likely to access support at all points of the dementia care pathway, so are more likely to seek help in a crisis or at a later stage in the condition." To the right of the text is a circular graphic containing a map of South Asia, with teal and blue abstract shapes overlaid on it.

- Hosted by **Race Equality Foundation**
- Resources for dementia awareness, diagnosis and assessment, post diagnostic support, including videos.
- Recommendations for clinicians and dementia workers, local team leads and managers and commissioners of services

A screenshot of a page from the ADAPT toolkit. On the left, there is a circular image of an elderly woman and man looking out at the sea, with teal and blue abstract shapes overlaid. On the right, the text reads: "Section 1: Interventions for people living with dementia", "INTERVENTIONS DEVELOPED IN THE UK", "A Punjabi adaptation of Cognitive Stimulation Therapy (CST)", "Where was this intervention developed? In the Slough Memory Service, UK", "What does the intervention involve? Cognitive Stimulation Therapy is an evidenced-based group intervention which typically runs twice a week across 14 or more sessions of themed activities, focusing on topics such as foods, music, word and number games. In the Slough Memory Service, staff have adapted the sessions to be more culturally appropriate and relevant to the Punjabi-speaking community (for example, the inclusion of brewing Masala tea and listening to Indian music). This is the only psychosocial intervention recommended by NICE.", "What is the research underpinning this intervention? Sharma S and Scott I (2016) Collaborating with service users to form a culturally tailored intervention: Punjabi Cognitive Stimulation. PPOF Bulletin 133: 32-38.", and "This paper provides reflections on the differences between the".

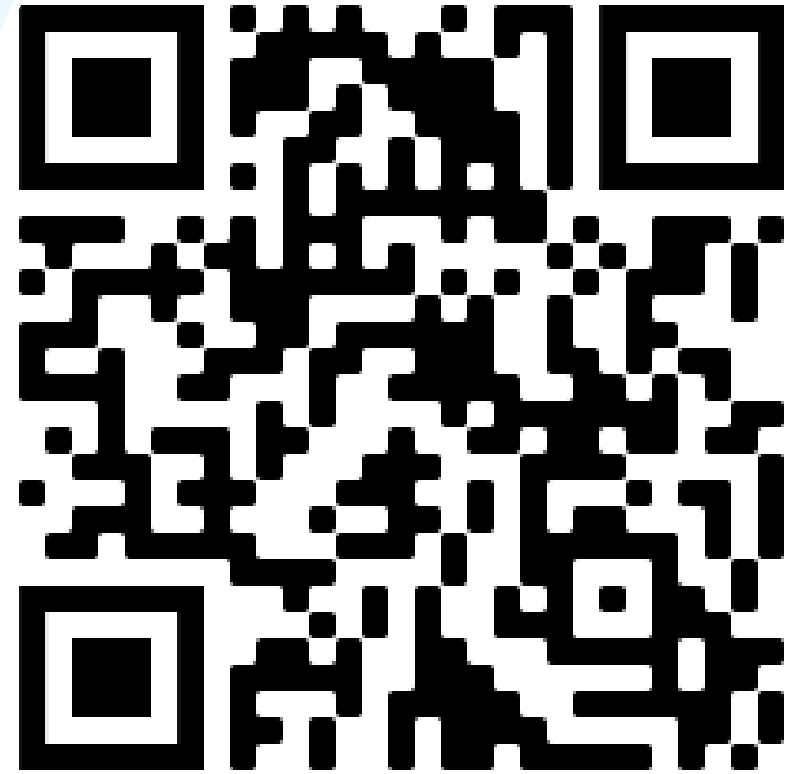


**Public  
contributor  
feedback  
on toolkit**

- *“If I as a carer had come across this toolkit at the start of this awful journey, it would have helped me to navigate my way around the system. I hadn’t been made aware of the services and support by any of the professionals after Mum’s long awaited diagnosis.”*
- *“This toolkit will help shine a light for people who have been scrambling around in the dark.”*
  - *“It is really important to show the female perspective and the importance of not making generalisations about people.”*

# Finding the ADAPT website

<https://raceequalityfoundation.org.uk/adapt/>











Questions ? Just ask

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John Haddow

Jagdish Brar-Orgill

Ros Weinberg

**Thank you**



UNIVERSITY OF  
GREENWICH

*Institute for Lifecourse  
Development*

# Summary of related resources to The Ageing Well Public Talk Series

## Podcasts

Vseteckova J & King J (2020) COVID-19 Interview podcast for The Retirement Café:  
['Ageing Well Under Lockdown'](#)

Vseteckova J & Broad E (2020) Podcast – Open University & The Parks Trust [Keep Me Walking – researching with people living with dementia and their carers](#) –

Vseteckova J (2020) Podcast – [Areas of research with The Open University](#)

Broad E, Methley A & Vseteckova J (2021) Podcast OU & The Parks Trust & Northamptonshire Healthcare NHS Foundation Trust – [Spotter sheet and mindful walking](#).

Vseteckova J, Methley A, Broad E (2021) Podcast OU & The Parks Trust & Northamptonshire Healthcare NHS Foundation Trust [Preventing brain decline while ageing](#)



## Ageing Well Public Talks

Methley A, Broad E, Vseteckova J (2021) Podcast OU & The Parks Trust & Northamptonshire Healthcare NHS Foundation Trust [Walking therapy](#)

Vseteckova J, Methley A, Broad (2021) Podcast OU & The Parks Trust & Northamptonshire Healthcare NHS Foundation Trust [Understanding our memory](#)

Araya Y , Broad E, Vseteckova J (2022) [Engaging with our environment](#)

Joannidi H, Araya Y, Broad E & Vseteckova J (2022) [Sense of self during aging: how mindfulness and nature can help](#)

The above podcasts can be also seen on [The Parks Trust YouTube Channel](#)



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Methley A & Vseteckova J & Jones K (2020) [Green & Blue & Outdoor spaces](#)

Vseteckova J, Borgstrom E, Whitehouse A, Kent A, Hart A (2021) [Advance Care Planning \(ACP\)](#)

Vseteckova J (2020) [Walking the Parks with The OU and The Parks Trust](#)

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Hedges V & Vseteckova J (2023)

[What should I expect when I am nearing the end of my life?](#)

Joannidi H, Araya Y, Broad E & Vseteckova J (2022)

[Sense of self during aging: how mindfulness and nature can help](#)

Mehta S, Vseteckova J (2023) [Ageing, health inequalities and person centred care](#)

Mehta S, Vseteckova J (2023) [Ageing, health inequalities and integrated approach to care](#)

Araya Y, Broad E, Vseteckova J (2023) [Ageing well by connecting and learning about nature outdoors](#)

## **Care and caring related**

Vseteckova J, (2020) [How to age well, while self-isolating](#)

Vseteckova J, (2020) [SHORT FILM - Ageing Well in Self-Isolation](#)

Vseteckova J, (2020) [ANIMATION - Keeping healthy in Self-Isolation](#)

Vseteckova J et al (2020)  
[COVID-19 The effects of self-isolation and lack of physical activity on carers](#)

Taverner P, Larkin M, Vseteckova J, et al. (2020) [Supporting adult carers during COVID-19 pandemic](#)

Robb M, Penson M, Vseteckova J, et al. (2020) [\*\*Young carers, COVID-19 and physical activity\*\*](#)

Penson M, Vseteckova J et al. (2020) [\*\*Older Carers, COVID-19 and Physical Activity\*\*](#)

Vseteckova J & Methley A (2020) [\*\*Acceptance Commitment Therapy \(ACT\) to help carers in challenging COVID-19 times\*\*](#)



**Ageing Well  
Public Talks**

**[AGEING WELL PUBLIC TALK SERIES WEBSITE](#)**

**[Ageing Well Public Talks' Series 2023/2024](#) repository on ORDO Collections**

**[Ageing Well Public Talks' Series 2022/2023](#) repository on ORDO Collections**

**[Ageing Well Public Talks' Series 2021/2022](#) repository on ORDO Collections**

**[Ageing Well Public Talks' Series 2020/2021](#) repository on ORDO Collections**

**[Ageing Well Public Talks' Series 2019/2020](#) repository on ORDO Collections**

**[Midlife MOT OpenLearn Course](#)**

**[OpenLearnCreate Course on 'Ageing Well' 2019/2020](#)**

**[Home exercise no equipment – no problem](#) *Blog***