

# From Seldom Heard to Seen and Heard

September 19<sup>th</sup> 2017

Royal College of Nursing

@Dementia\_Action  
#dementiaseenandheard  
#DementiaAction

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# Chairs' opening remarks

**Nuzhat Ali**

Public Health England

and

**Shelagh Robinson**

living with dementia

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# Update from our host

**Stephanie Aiken**

Royal College of Nursing

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# Introduction to From Seldom Heard to Seen and Heard campaign

**Kelly Kaye**

DAA

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From Seldom Heard to Seen and Heard

A Dementia Action Alliance campaign launch

19 September 2017

**Seldom Heard Groups - an overview**

Toby Williamson  
Independent Consultant

**Toby Williamson Consultancy**

# “Seldom-heard groups”

*“‘Seldom heard’ is a term used to describe groups who may experience barriers to accessing services or are under represented in healthcare decision-making”*

NHS involvement 2017

# Seldom-heard groups

- Rural communities
- Black, Asian and minority ethnic communities (BAME)
- Gypsies and travellers
- Lesbian, gay, bisexual, trans + (LGBT+)
- Asylum seekers and refugees
- Young carers
  
- Also, teenagers, employees, people with mental health issues

*(NHS involvement 2017)*

# Dementia

## Equity and Rights



**Toby Williamson Consultancy**



# From “seldom-heard” to equity and rights

- Age (very old and young onset dementia)
- Disability (cognitive - learning disabilities - and physical)
- Women (and men?)
- Socio-economic status
  
- Prison population
- Homeless

# Seldom-heard groups – challenges

- Lack of (cultural) awareness
- Services that are not responsive or accessible
- Practices that exclude
- Language barriers
- Discrimination and “isms”
- The experience of inequalities and social injustice
- Avoidance

# Seldom-heard groups - responses

- Understand their needs and priorities
- Find out how they like to get involved
- Understand the way they preferred to be communicated with and what tools they use
- Find out who they trust and have good relationships with
- Don't expect everyone to feedback in the same way  
*(NHS Involvement 2017)*
- What's in it for them?

# *Dementia, Equity and Rights (2016)*

## Overarching themes

- Understanding each person and carer as an individual
- Consider different pathways to diagnosis
- Explore tailored support options following diagnosis, including peer support , for people with dementia and carers
- Work through community intermediaries and locally tailored public awareness campaigns
- Professional understanding of equity issues
- Using local data resources, research and evaluation

# Conclusion

- It's an issue of awareness, provision and access to appropriate services
- It's an issue of resources – so it's an issue of political will
- It's an issue of rights
- What are you doing – what actions can you take?

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# Panel discussion: Chaired by Innovations in Dementia

Mike Parish, Tom Hughes, Shahid  
Mohammed, Sarah Lancaster, Patrick  
Ettennes, Tracey Shorthouse

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National Dementia Action Alliance

# Group discussions, opening with feedback from roundtables

Sally Knocker: LGBT+, Junaid Dowool: Prisons,  
Karen: Learning Disabilities

South Asian – Akhlak Rauf

Gypsies and Travellers – Mary Tilki

Irish - Jo Higgins

African Caribbean – David Truswell

Learning Disabilities – Christine Burke and Pat Charlesworth

LGBT+ - Sally Knocker

Prisons – Junaid Dowool

Social Deprivation – Hilary Kinsler

Young Onset – Donna Chadwick

Dodd - LD

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# Pledges

Group discussions on how delegates will commit to supporting people affected by dementia from seldom heard groups

- What actions currently are you undertaking for seldom heard groups?
  - What actions will you take?
  - Fill in pledge today – give back to us please

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# Chairs' closing remarks

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Public Health England

and

**Shelagh Robinson**

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