

September 19th 2017 Royal College of Nursing



Chairs' opening remarks

Nuzhat Ali

Public Health England

and

Shelagh Robinson

living with dementia

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#dementiaseenandheard
#DementiaAction



Update from our host

Stephanie Aiken Royal College of Nursing



Introduction to From Seldom Heard to Seen and Heard campaign

Kelly Kaye DAA

A Dementia Action Alliance campaign launch

19 September 2017

Seldom Heard Groups - an overview

Toby Williamson
Independent Consultant

"Seldom-heard groups"

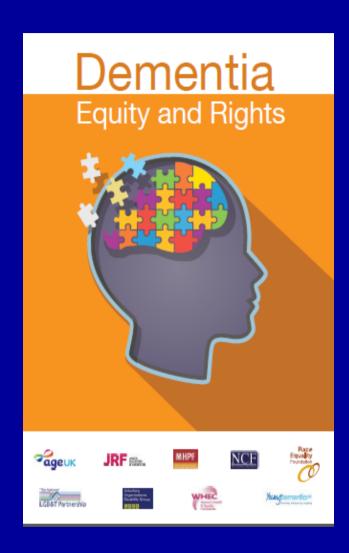
"'Seldom heard' is a term used to describe groups who may experience barriers to accessing services or are under represented in healthcare decision-making"

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)



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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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



Chairs' closing remarks

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