Public Health
England

Equality and health inequality issues in dementia

Summary of event – 7 May 2014

About Public Health England

Public Health England exists to protect and improve the nation's health and wellbeing, and reduce health inequalities. It does this through advocacy, partnerships, world-class science, knowledge and intelligence, and the delivery of specialist public health services. PHE is an operationally autonomous executive agency of the Department of Health.

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339

Contents

Introduction and overview

On 7 May 2014 Public Health England (PHE) hosted an event to consider equality and health inequality issues in dementia. Forty attendees participated, including leading figures from the voluntary, community, and statutory sectors, alongside people living with dementia.

This document is aimed at partners in all sectors interested in understanding and addressing equality and health inequality issues in dementia. It summarises some of the main themes emerging from the discussion, including possible next steps. Whilst it seeks to be an accurate record, it is not comprehensive, and should not be interpreted as ascribing particular views to particular individuals or organisations.

Public Health England takes a wide interest in equity. The Health and Social Care Act established specific legal duties on health inequalities which PHE must meet. This means that PHE must demonstrate that it has taken into account the need to reduce health inequalities in all its work and will need to provide evidence of compliance with the duties. Health inequalities in England exist across a range of indicators, including some of the nine protected characteristics of the Equality Act 2010 and socioeconomic status and geography.

Aims of the event

The aims of the event were to:

- explore opportunities for a new national focus on inequalities within the dementia population and the dementia carer population. Considering questions such as:
    - Which groups are disadvantaged in their experience of dementia, and in what ways?
    - What can policymakers, commissioners, and providers do to address these?
    - Where can we identify priorities for joint action?

- develop commitment across sectors and interests to work together on a shared process over the course of the year with the aim of:
    - raising the profile of the need to tailor our response to dementia in light of a range of different equality characteristics, and
    - stimulating improvement at all relevant levels of the health and care systems

Scope of the event

The aim was to focus on equity issues within the population affected by dementia (including carers), rather than between the those affected and the wider population. Nationally and locally, there is significant activity to improve the experiences of people with dementia and their carers. In a national policy context this is being taken forward through the Prime Minister’s Challenge on Dementia[1], building on progress made through the National Dementia Strategy[2]. This includes three ‘champion groups’ each focusing on 1 of the main areas for action: driving improvements in health and care, creating dementia friendly communities and improving dementia research.

Our intention with this event was to begin to add additional nuance that would see approaches better tailored to the hugely varying needs of people within the population, be that because of ethnicity, geography, age, disability, etc.

With this is mind our starting point was to structure our thinking around the protected characteristics in the Equality Act, and some of the main causes of health inequalities.

The protected characteristics in the Equality Act:

- age
- disability
- race/ethnicity
- religion or belief
- sex
- gender reassignment
- sexual orientation
- marriage and civil partnership
- pregnancy and maternity

Health inequalities are also associated with characteristics such as:

- socio-economic status
- geography
- seldom heard/vulnerable groups

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[1] http://dementiachallenge.dh.gov.uk/about-the-challenge/
[2] https://www.gov.uk/government/publications/living-well-with-dementia-a-national-dementia-strategy

Presentations – setting the scene

The event began with 3 presentations intended to bring everyone to a common level of understanding and provoke discussion on how to improve. Slides for the 3 presentations are attached.

“Overview of equality and health inequality issues and dementia”. Jo Moriarty, Social Care Workforce Research Unit, King's College London

Taking the Equality Act as her starting point, Jo Moriarty gave an overview of the ways dementia is relevant for the following equality characteristics:

- age
- disability, including learning disability
- gender
- sexual identity
- gender identity
- ethnicity
- religion
- socio-economic status

“A workforce and provider perspective – ethnic identity and cultural diversity in dementia care: a person-centred approach”. Karan Jutlla, The Association for Dementia Studies, University of Worcester

Due to illness Karan’s presentation was delivered by Jo Moriarty. Karan’s presentation considered the person-centred approaches in which a nuanced understanding of an individual’s circumstances could be the key to reflecting their cultural needs appropriately alongside all their other needs. This is contrasted with assumption about what their needs might be because they are perceived to be part of a particular community.

“A commissioner’s perspective – focus on Enfield”. Paul Allen, Older People's Commissioning Manager, Enfield Council

Paul Allen gave an overview of Enfield’s efforts to tailor their approach to dementia for different groups, emphasising the importance of partnership with community organisations.

Main discussion – opportunities for improvement and developing an action plan

This section gives an overview of the main points raised in discussion.

Supporting individuals

- *The whole person* - Do not assume that because people share one characteristic they will necessarily have similar needs. Individuals are not defined solely by individual communities and characteristics, and a view of the whole person is needed.
- *The distinction between person-centred approaches and cultural competence:* 'person-centred approaches' to dementia help to expose an individual's needs. This may include characteristics such as their cultural heritage, sexual orientation, or disabilities. 'Cultural competence' is about understanding the complex role that an individual's cultural background can play in their current experience and needs.
- *Carers' needs may be very different*: carers can face different challenges to the cared for in a given community, especially if they are of a different generation with different expectations.
- *Information for people with dementia and carers:* information is vital to people's experience of dementia, and needs to be presented in a range of forms that are sensitive to different needs (eg disabilities) and contexts (eg ethnicity).
- *Engaging people with dementia*: people with dementia should be involved in discussions about the design of services, so their personal experience is reflected.
- *'Diagnostic overshadowing'*: diagnostic overshadowing (ie: over-attributing an individual's symptoms to one particular condition) is not just limited to other diagnoses overshadowing dementia (eg learning disability). Dementia can also overshadow issues like sensory loss, that can affect quality of life.
- *Sharing relevant information with consent:* individuals may not feel comfortable repeatedly disclosing personal information such as their sexual orientation face to face, but may consent for this to be shared with professionals in advance.
- *Dementia as a disability:* Dementia can be defined as a disability, and therefore subject to protection via the Equality Act and related legislation.

Supporting communities

- *The preconceptions of people in a community you feel part of can significantly affect your experience of dementia*: at a community level, improving attitudes to dementia and understanding is vital. That said, there is no single 'dementia friendly community'

– there are communities within communities that can provide or inhibit vital support networks.

- *Public understanding of dementia varies for different reasons*: Understanding of dementia is relatively low in all communities, but the nature of misconceptions and stigma can very significantly.
- *Tailoring public information campaigns:* local and national campaigns need to be tailored to resonate with very different understanding and barriers in different communities. They need to reach beyond mainstream media and communicate via other intermediaries eg religious institutions.
- *Actively involving small local groups:* Small local groups that seek to represent people with particular characteristics may not be immediately visible to commissioners, nor have a good understanding of dementia. Making these groups aware of dementia and directly engaging them in efforts to improve services can unlock local improvement. They can even become part of the pathway if professionals are aware of their role and groups are supported to grow.
- *"Hidden groups"*: there is a responsibility on commissioners to seek out individuals that might be particularly under supported.

Supporting commissioners

- *Commissioner understanding:* many commissioners want to do more to address equity issues in dementia but very often don't understand how.
- *Assemble the evidence base and best practice examples:* there is reasonable evidence of the relationship between many of the equity characteristics and dementia, and pockets of excellent practice. However, this is dispersed and there is no single summary to drive improvement. Commissioners will be better able to put the evidence base into practice if given advice on how to appropriately construct JSNA and JHWS for equality issues and dementia.
- *Understanding impact:* action to better tailor approaches to dementia for individuals and communities is expected to deliver benefits to quality of life alongside reductions in distressing and expensive crises caused by unmet need. A more nuanced understanding of these impacts and cost effective interventions to deliver them would help implementation.
- *Intelligence:* Currently diagnosis data are not broken down by useful characteristics such as age, sex, ethnicity, etc. All partners need better intelligence to understand which individuals and groups are experiencing differential access to diagnosis and support. Drawing together data from local systems and databases could have a significant impact eg health, social care, citizenship portals used by local authorities, parks, schools etc.

Supporting professionals

- *Professional understanding and training:* professionals often need much greater awareness and support to deliver person centred, culturally competent care. This includes all levels of professional, from domiciliary care workers to allied health professionals to general practitioners. This may involve changing approaches to become more actively person centred ('changing hearts and minds'), as much as learning specific information about groups and characteristics.

Supporting the wider system

- *Sustainability:* 'Initiatives' in dementia are often time limited. The challenge is to create sustainable solutions that reduce inequalities.
- *Support for local evaluation:* local projects need help to demonstrate their impact and enable spread of best practice across the country.
- *Seek opportunities to improve current policy:* there is currently a large amount of effort going into improving dementia care and support. There is an opportunity to review these to ensure they are appropriately tailored. For example, person centred approaches might be built into new training models.

Next steps – get involved

Partners will be seeking to turn these reflections into action over the coming months.

In particular, several partners are coming together to create an evidence review on equality and health inequality issues in dementia for local commissioners. The aim will be to bring together disparate sources of information and analysis into a single document that can help commissioners understand the issues, and learn from case studies of good practice around the country.

In addition, following our event, several partners have agreed to consider how to build equity insights into their future work programmes.

We plan to hold a further event towards the end of 2014 for partners to review progress and consider next steps.

To get involved or for any more information, please email dementiaequalities@phe.gov.uk.

Annex 1- attendees

Attendee	**Organisation**
Alli Anthony	Alzheimer's Society – Connecting Communities Project
George McNamara	Alzheimer's Society – Head of Policy
Ruth Hannan	Carers Trust
David Truswell	Central and North West London NHS Foundation Trust
Catherine Murray-Howard	Community Integrated services
Duncan Tree	CSV
Simon Kitchen	Dementia Action Alliance
Lorraine Jackson	Department of Health
Ian Sheriff	DFC Rural Communities Task & Finish Group
Ramesh Verma	EKTA
David Sallah	Health Education England
Charlotte Curran	Irish in Britain
Mary Tilki	Irish in Britain
Helen Efozia	Kensington & Chelsea and Westminster Memory Service
Jo Moriarty	Kings College London - Social Care Workforce Research Unit
Valeska Matziol	Lesbian & Gay Foundation; National LGB&T Partnership
Anna Gaugin	Life Story Network
Helen Kay	Local Government Association
Paul Allen	London Borough of Enfield
Toby Williamson	Mental Health Foundation
Gill Boston	National Care Forum / Voluntary Organisations Disability Group
Alistair Burns	NHS England – National Clinical Director for Dementia
Michelle Plaice	NHS England: Dementia
Christina Marriott	NHS England: Health inequalities
Hannah Rees	NHS England: Health inequalities
Claire Bache	Public Health England: Dementia

Diana Kirby	Public Health England: Dementia
Janani Paramsothy	Public Health England: Dementia
Richard Kelly	Public Health England: Dementia
Ros Louth	Public Health England: Dementia
Sally Warren	Public Health England: Director of programmes
Ann Marie Connolly	Public Health England: Health Equity and Impact
Simon Rippon	Public Health England: Knowledge & Intelligence
Craig Lister	Public Health England: NHS Health Checks
Anne-Marie Hamilton	Public Health England: Strategic programmes
Jabeer Butt	Race Equality Foundation
Sophie Hodge	Royal College of Psychiatrists
David Cundy	Social Care Institute for Excellence
Simon Chapman	The National Council for Palliative Care
Zoe Palmer	Women’s Health and Equality Consortium

We were also delighted to have participation from three individuals living with dementia.

Annex 2 – presentations

Please see attached file for a copy of the presentations given at the event.