

## **Contents**

# **Equality Impact Assessment of the Post-Diagnostic Support (PDS) in Primary Care Programme**

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#### 1. Introduction

Healthcare Improvement Scotland is required to assess the impact of applying a proposed new or revised policy or work programme, against the needs of the general equality duty, namely the duty to:

- Eliminate unlawful discrimination, harassment and victimisation and any other conduct prohibited by the Equality Act 2010
- Advance equality of opportunity between people who share a protected characteristic and people who do not share it; and
- Foster good relations between people who share a protected characteristic and people who do not share it

The relevant protected characteristics are:

- age
- disability
- · gender reassignment
- pregnancy and maternity
- race
- religion and belief
- sex
- sexual orientation
- marriage and civil partnership (relates to the elimination of discrimination only)

The recommendations made in this assessment seek to improve equality and to help meet the specific needs of people with the relevant protected characteristics, where possible.

Our impact assessment also considers if the PDS in Primary Care Programme has the potential to impact on health inequalities.

Health inequalities are disparities in health outcomes between individuals or groups. Health inequalities arise because of inequalities in society, in the conditions in which people are born, grow, live, work and age.

Health inequalities are influenced by a wide range of factors including access to education, employment and good housing, equitable access to healthcare, individuals' circumstances and behaviours, such as their diet and how much they drink, smoke or exercise and income levels.

The potential impact of the PDS in Primary Care Programme on an individual's human rights has also been considered. The programme will follow the PANEL principles of the Charter of Rights for People with Dementia and their Carers in Scotland (2009). See Appendix A.

Giving due regard to these factors is also intended to help Healthcare Improvement Scotland to meet its duties under the Fairer Scotland Duty, which requires public bodies to reduce inequalities of outcome caused by socioeconomic disadvantage.

## 2. Aim/purpose of the PDS in Primary Care Programme

The aims and objectives of the PDS in Primary Care Programme 2018-2021 are:

- To implement and evaluate the delivery of dementia post-diagnostic support from three GP cluster sites (27 practices in total), engaging the wider primary care team, social work, housing and the voluntary and independent sector
- To understand which groups of individuals benefit from post-diagnostic support in primary care, demonstrating those benefits and the scope for delivery of improved outcomes
- To understand the distribution of need and demand for post-diagnostic support within the primary care setting
- To assess the cost and benefits of this approach to individuals and to the health and social care system
- Share learning across Scotland and wider

## 3. Assessment of impact

The groups of people who may be impacted by this programme are as follows: age, disability, gender reassignment, race, religion or belief, sex and sexual orientation. Please see below for what Focus on Dementia takes into consideration in its programmes.

Protected	Does the proposed programme have the potential to negatively
Characteristics	impact our ability to meet the general equality* duty in relation
	to any of the protected characteristics?
Age	Older people are well represented in our programme making up the vast majority of people living with dementia.
	People living with dementia also includes young onset dementia (under 65). Access to support at each of the innovation sites is available to people under and over 65.
Disability	Many GP patients in the programme are more likely to have disability due to their general age and frailty. This includes a range of co-morbidities, sensory impairment and decreased mobility.
	As part of their support from within primary care, GP patients with dementia will be referred to trained staff for aids and adaptations to support them with physical ill health and disability.
Gender reassignment	If a patient with dementia has gender reassignment they may experience distress around:
	<ul><li>Recalling transition, disclosure, outing and confidentiality</li><li>Attitudes and assumptions</li></ul>
	Hormones and overlap with other medication
Marriage and civil partnership (relates to the elimination of discrimination only)	See 'sex', 'sexual orientation' and 'gender reassignment' for related issues
Pregnancy/ maternity	Not applicable due to patient age

Race	People with minority ethnic backgrounds with dementia and carers should have equity of access to PDS however access to care may be impacted by available information in specific languages, understanding and cultural views of dementia, which can vary with culture.
	If someone has a first language, they may feel more fluent, comfortable or have better cognition of it and revert back to it which may cause communication issues  • Sense of isolation if in white institutional culture
	Culturally appropriate knowledge of staff/links with community
	May only have access to long-term memories from when they experienced overt hostility
	Family may have similar issues
Religion or belief	May influence how people with dementia and caregivers understand and/or relate to dementia
	https://www.tandfonline.com/doi/abs/10.1080/13674676.2013.816941
	https://onlinelibrary.wiley.com/doi/abs/10.1111/jep.13412
Sex	Women are well represented in the patient group as dementia has a higher incidence in women. Gender should not impact on care.
Sexual orientation	It is thought that 2.6 % of people in Scotland identify as lesbian, gay or bisexual (Office for National Statistics 2019)
	As dementia progresses, LGBT people may feel like they are back in an earlier time in their life and this could cause distress
	<ul> <li>Being out, to what extent and to whom/returning to closet/disclosure</li> </ul>
	Outing and confidentiality
	<ul> <li>Reminiscence work, which can be therapeutic for many people with dementia, may distress but could also be a positive experience if tailored to the individual</li> </ul>
	Attitudes and assumptions, perception of institution and safety     Socializing and maintaining links with (LCRT)
	<ul> <li>Socialising and maintaining links with (LGBT)     community/isolation/reference points (queer culture/music/TV)</li> </ul>
	Relations - less likely to have children and more likely to be estranged from family. Family/loved ones may be 'chosen family'. Sensitivity required in supporting Life Story work

## 4. Recommendations for change

The following actions are recommended:

- Primary care innovation sites should access training and resources and consider activities at a local level to reduce the potential for negative impacts on health inequalities. This could include:
  - a. Equalities training/awareness raising opportunities
  - b. Accessing and working with translation services
  - c. Conducting a self-assessment using the PDS Quality Improvement Framework which prompts the need for conducting a site EQIA and gives guidance on what might help.
- 2. Innovation site contract to include information encouraging teams to consider potential impacts on health inequalities for people with dementia in their care as a result of improvement activities.

It is not believed the actions recommended will create any new, adverse impacts.

## 5. Monitoring and review

This work will be monitored within the governance structures of Healthcare Improvement Scotland and the Community Delivery Group.

The EQIA will be monitored as part of the project management processes for the PDS in Primary Care Programme.

## 6. Who carried out the impact assessment?

The impact assessment of the PDS in Primary Care Programme was carried out by:

#### EQIA completed by -

Julie Miller, Improvement Advisor Jane Millar, Senior Project Officer

#### EQIA reviewed by -

Lynn Flannigan, Senior Improvement Advisor

#### 7. Contact Information

If you have any comments or questions about this assessment, or if you would like us to consider producing it in an alternative format, please contact us:

Email: his.focusondementia@nhs.scot

### Appendix A

### How this programme follows the PANEL principles

Participation: Everyone has the right to participate in making decisions that affect them. Participation should be meaningful and give attention to issues of accessibility, including access to information in a form and a language which can be understood.

- Stakeholder events and focus groups to understand current state
- · Representation on relevant groups
- Ongoing collaboration with Scottish Dementia Working Group (SDWG) and National Dementia Carers Action Network (NDCAN)
- Regular feedback from people with dementia and carers built into evaluation and measurement plans
- Ensuring opportunities for people with dementia to influence our work are maximised, taking a strengths-based approach

Accountability: Accountability requires effective monitoring of our work, ensuring that human rights standards are met. For accountability to be effective there must be suitable procedures in place to ensure feedback is considered and where appropriate acted upon.

- Stakeholder events and focus groups to understand current state
- Representation on relevant groups
- Ongoing collaboration with SDWG and NDCAN
- Regular feedback from people with dementia and carers built into evaluation and measurement plans
- Ensuring opportunities for people with dementia to influence our work are maximised, taking a strengths-based approach
- Building engagement into our operating procedures and regularly monitoring these

Non-discrimination and equality: Nobody should experience because of their age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex, sexual orientation or any other status.

- The EQIA will be monitored and updated on a regular basis
- The QIF stipulates that PDS services will conduct their own EQIA as part of improvement action plans

<b>Empowerment:</b> People should
be informed of and understand
their rights. People should be
supported to claim their rights
where necessary.

- Ensure robust project communication plan which takes into account equality and diversity issues and includes contact details
- Ensure opportunities for people with dementia are maximised, taking a strength based approach
- **Legality:** The full range of legally protected human rights must be respected, protected and fulfilled.

A human rights based approach requires the recognition of rights as legally enforceable entitlements, and is linked in to national and international human rights law.

 Ensure project is compliant with legislation and seek advice from subject matter experts; Clinical Leads, Rosie Tyler-Grieg (Healthcare Improvement Scotland) and local equality and diversity leads.