

An Equality Impact Assessment of

Focus on Dementia

Post-Diagnostic Support Work Programme

(April 2017 – March 2022)

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Equality Impact Assessment of Post-Diagnostic Support (PDS) work 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
- 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 report seek to improve equality in our Post-Diagnostic Support (PDS) improvement programme and to help meet the specific needs of people with the relevant protected characteristics, where possible.

Our impact assessments also consider if the PDS 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 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 programme

The aims and objectives of the PDS work programme are:

- To improve access, experience and quality of PDS for people with dementia, carers and staff
- Create an overarching Learning System for PDS
- Establish a national PDS Leads network
- Establish a national dementia practitioner network
- Establish fora for network activity
- Collaborate with people with dementia, carers and practitioners to create a Quality Improvement Framework for high quality PDS
- Develop resources to support PDS activity
- Test the delivery of/or closer alignment of PDS from/to primary care settings including activity to encourage timely diagnosis
- 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 Characteristics	Does the proposed programme have the potential to negatively impact our ability to meet the general equality* duty in relation to any of the protected characteristics?
Age	<p>Older people are well represented in our programme making up the vast majority of people living with dementia.</p> <p>People with dementia also includes young onset dementia (under 65). People diagnosed with dementia at any age, over and under 65 are eligible for PDS. All resources/projects produced and facilitated by the PDS programme are relevant for people with dementia of any age. Young onset dementia is currently being scoped as part of our PDS Leads Group.</p>
Disability	<p>People with dementia are more likely to have disability due to their condition, general age and frailty. This includes a range of co-morbidities, sensory impairment and decreased mobility.</p> <p>Our work promotes high quality PDS so that people with dementia and their carers have access to specialist PDS practitioners who can support access to aids and adaptations to help with physical ill health and disability.</p>
Gender reassignment	<p>We recognise that if a person with dementia has gender reassignment they may experience distress around:</p> <ul style="list-style-type: none">• Recalling transition, disclosure, outing and confidentiality• Attitudes and assumptions• 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 age group covered by the programme.
Race	<p>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</p> <ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • May influence how people with dementia and caregivers understand and/or relate to dementia <p>https://www.tandfonline.com/doi/abs/10.1080/13674676.2013.816941 https://onlinelibrary.wiley.com/doi/abs/10.1111/jep.13412</p>
Sex	Women are well represented as dementia has a higher incidence in women. Gender should not impact on care.
Sexual orientation	<p>It is thought that 2.6 % of people in Scotland identify as lesbian, gay or bisexual (Office for National Statistics 2019)</p> <p>As dementia progresses, LGBT people may feel like they are back in an earlier time in their life and this could cause distress</p> <ul style="list-style-type: none"> • Being out, to what extent and to whom/returning to closet/ disclosure • Outing and confidentiality • 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 • Attitudes and assumptions, perception of institution and safety • Socialising and maintaining links with (LGBT) community/ isolation/reference points (queer culture/music/TV) • 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:

1. PDS services should access training and resources and consider activities at 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
2. PDS Learning System activity to include information encouraging PDS practitioners to consider potential impacts on health inequalities for people with dementia in their services as a result of improvement activities
3. Focus on Dementia will undertake an exploration of access to PDS in relation to people with protected characteristics and share findings and recommendations for improvement via its learning system.

It is not believed the changes 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 Focus on Dementia Community Delivery Group.

The EQIA will be monitored as part of the project management processes for the PDS programme.

6. Who carried out the impact assessment?

The impact assessment of the PDS 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

<p>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.</p>	<ul style="list-style-type: none">• 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
<p>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.</p>	<ul style="list-style-type: none">• 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
<p>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.</p>	<ul style="list-style-type: none">• 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

<p>Empowerment: People should be informed of and understand their rights. People should be supported to claim their rights where necessary.</p>	<ul style="list-style-type: none"> • 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
<p>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.</p>	<ul style="list-style-type: none"> • 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