Written evidence submitted by by Professor Linda Clare (FGP0191)

Submitted by Professor Linda Clare (ScD) on behalf of the IDEAL Programme, University of Exeter Medical School, and Sussex NHS Commissioners.

Summation

1.0 Primary care is, and will increasingly be, the front line responding to people with dementia. The future of General Practice needs to consider this specific population and take steps to prepare how best to support them.

1.1 We will address:

- The specificity of the need for sustainable and flexible general practice and primary care services for people affected by dementia
- An example of best practice which would make general practice more sustainable in supporting people affected by dementia

The research background

2.0 Linda Clare, Professor of Clinical Psychology of Ageing and Dementia, directs the Centre for Research in Ageing and Cognitive Health (REACH) at the University of Exeter, and is chief investigator for the IDEAL cohort study of people with dementia and carers, an Alzheimer's Society Centre of Excellence. IDEAL – Improving the experience of Dementia by Enhancing Active Life – studies how to live well with dementia over time, from two perspectives: people with dementia, and carers. A longitudinal study, IDEAL has been researching since 2014. IDEAL has previously received funding support from the Economic and Social Research Council and National Institute of Health Research.

2.1 Sussex NHS Commissioners comprise three Clinical Commissioning Groups (CCGs) which are part of the Sussex Health and Care Partnership ICS. This includes the team which piloted and rolled-out the award-winning Golden Ticket model for people with dementia and their carers. This model won the GP Forward View Innovations category for 'using social prescribing and supporting self-care' at the 2017 General Practice Awards.

What are the main barriers to accessing general practice for people with dementia?

3.0 There are over 850,000 people with dementia in the UK and this number is set to double in the next 20 years. Primary care teams are increasingly tasked with clinical management and even diagnosis of people with dementia, a task for which many practitioners feel insufficiently trained and supported. Dementia is a complex condition that presents many challenges for diagnosis and management. This is compounded after years of austerity by a lack of adequate community and social care resources, so that GPs have few options to suggest to people with dementia and their family carers who are struggling. Providing good care for people with dementia requires time, something that over-stretched practitioners often lack, as well as high levels of skill, knowledge and understanding.

3.1 Research findings from the IDEAL longitudinal cohort study of people with mild-to-moderate dementia and their family carers confirms that the GP is the first port of call for people with dementia

and the family members who support them. Of the 1537 people with dementia in the cohort interviewed at the first wave of assessment, 65% had seen their GP in the previous 3 months, and 48% a practice nurse. Longitudinal data indicates that at each assessment point around two-thirds have seen their GP in the previous three months. IDEAL research indicates the many psychosocial factors that influence capability to live well with dementia for both the person affected and the carer. The range of psychosocial needs is highly individual, as is the support required to enable people to maintain a reasonable quality of life and prevent unnecessary or excess disability arising for example as a consequence of isolation or depression, which may lead to the need for clinical intervention. Difficulties can emerge suddenly and unpredictably, but need to be addressed quickly.

3.2 While not always a GP, having a named health professional to contact is important for people affected by dementia, who can get caught in a complex healthcare system. People living with dementia often have other attendant conditions, making the organisation of care more challenging for all involved. Pleasingly, our COVID-19-specific research shows a significant increase in the number of carers reporting that they have a named health professional whom they could contact at any time, compared with our pre-pandemic data. The number reporting that this professional was in place due to the dementia diagnosis (rather than another health condition) had also seen a significant increase. We encourage this upward trend, since continuity is often key for people affected by dementia feeling properly supported.

3.3 The NHS plan for improving access for patients and supporting general practice focuses largely on those changes necessarily introduced by the COVID-19 pandemic. While important, these should not crowd out the possibility of addressing variation and encouraging good practice (the focus of the Plan's further action B) from pre-pandemic models, such as the Golden Ticket model. Indeed, improving the dementia pathway will address many of the difficulties the plan identifies, such as access challenges. We urge the committee to explore the Golden Ticket model of dementia care and how this might be implemented beyond Sussex.

How could general practice be more sustainable for supporting people with dementia? The Golden Ticket model

4.0 Overseeing care for more people with dementia than anywhere else in the UK, Sussex NHS Commissioners identified the implications of an ill-equipped primary care service, in terms of poor outcomes for patients and high numbers of acute hospital admissions, and decided to take action.

4.1 They developed a new partnership-based proactive care pathway, the Golden Ticket model. This was piloted at Buxted Medical Practice in East Sussex, with funding support from the Health Foundation's Innovating for Improvement Programme, and has since been extended to other practices in the area.

4.2 In the Golden Ticket model, practice teams are trained to understand and support people with dementia and their families. People with dementia and their family carers are offered opportunities for vital social contact and can access health and well-being interventions. A primary care worker is available, emergencies are dealt with promptly in a weekly clinic, and medications are proactively reviewed. Dementia guides from a local charity provide advice and help secure support from relevant agencies. GPs and their teams can get specialist advice from colleagues in the local Mental Health NHS Trust via a telephone helpline, multidisciplinary case review and crisis team. The early results from the pilot, validated by the Kent Surrey Sussex Academic Health Science Network, showed a 25% decrease

in acute hospital admissions, a 20% reduction in GP consultations, and importantly, reduced isolation and improved quality of life for people with dementia and carers.

4.3 Targeting the needs identified in IDEAL research, The Golden Ticket model is an example of best practice that could inspire other areas to develop similar solutions tailored to their local situation. Such models are needed to support the sustainability of general practice in the coming decades, and should be encouraged.

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