ASUME

Volunteering in Dementia

comparing

In the UK dementia care policy is devolved and, therefore, policy contexts differ between England and Scotland, the two countries where the ASUME UK fieldwork took place. However, the approach to dementia care in both countries is framed by national policies and actions.

In England, the national strategy Living well with Dementia (Department of Health 2009) and was followed up by two 'Prime Minister's Challenges' delivered in 2012 and 2015 which underpin objectives for dementia care and in Scotland, policy is framed by a series of three national strategies published in 2010, 2013 and 2017 (Scottish Government 2010, 2013, 2017). There are similarities in the delivery of healthcare with the UK National Health Service providing health care free at the point of need in both countries. However, when it comes to social care provided in people's homes and community settings, the main focus of the ASUME projects, there are important differences between the two countries.

In Scotland the national strategies have provided a framework for service provision as well drivers related to health service improvement targets. The headline policy in the earlier strategies was the promotion of early diagnosis and an increase was seen in the percentage of people with dementia receiving a diagnosis across Scotland. Other priority areas included acute hospital care and end of life care with the most recent strategy (Scottish Government 2017) promoting a community 'eight pillar' model that recognises the more complex needs people with dementia may have as the condition progresses (Alzheimer Scotland 2019).

The strategies underpin a flagship policy that provides everyone with a diagnosis of dementia at least one year of post-diagnostic support, with the broad aim to keep people at home for as long as possible.

As with the UK, dementia care in Norway is also framed by national policy in the form of two National Dementia Plans, one released in 2008 and one in 2016 (Norwegian Ministry of Health and Care Services, 2008; 2016). Within the first plan there was a focus on formal services particularly on the provision of specialist 'day activity services' for people with dementia that were seen as a key link in the chain of services, supporting people to live at home. Since the first plan was published in 2008 there has been a two-fold increase in the number of people with dementia accessing such services (Norwegian Ministry of Health and Care Services, 2016) and the second plan continues to support this initiative. Another impact of the first plan has been the increasing recognition by municipalities of the importance of providing support for families with dementia demonstrated by almost 80% of municipalities now having dementia teams or coordinators to support people following a diagnosis.

The 2020 plan as continued with many of the objectives of the first plan but has changed focus somewhat to the community and to the aim of enabling communities and individuals to support themselves. The objective is for people with dementia to continue to live meaningful lives with support provided in their communities rather than moving into institutional settings. Community based services offer many opportunities for volunteers to become involved in dementia care.

The dementia plans, strategies and challenges across the three countries all emphasise the importance of community support for people with dementia and the role of a range of organisations to provide this support across health and social care. It is likely that with the stronger focus on community that third sector organisations will work alongside statutory services to support people with dementia and that across these organisations volunteers will play an important role.

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Insights from the cross-cultural communication

This table outlines some interesting ASUME themes between the UK and Norway. The comparison between the two studies is cautious, however, due to the differences in response rates (the UK study involved 70 interviews for example). What we hope can emerge are key talking points to consider for research in the future.

ASUME	Similarities	Differences
Attract	Volunteers tend to be older, women, retired Personal experience of dementia was a key common element between volunteers	Cultural differences in understanding about altruism and how this is framed
Sustain	Training experiences generally positive Volunteers saw their role as long-term and did not plan to stop	Volunteers in Norway were very positive about their organisation, UK volunteers tended to be more critical of wider support
Understand	There was a common link between volunteers and feelings of bereavement	No prominent focus on supporting carers in Norway, but this was common in the UK
Motivate	Social connection and interaction are dominant motivators for volunteering	UK Volunteers often expected more support, while Volunteers in Norway expressed more personal responsibility for meeting challenges.
Environment	Volunteers linked a variety of home and community settings via their support and activity with those living with dementia.	The Norwegian context, translation and understanding of 'care homes' – 'Helsetunet' – lends to a more active understanding of volunteering, interaction and activity.

Helsetunet is a common name for a nursing home/day centre, and is the name of one of the nursing home/day centre where the Activity Friends undertook their volunteering and is the Norwegian name that related to older Norwegian houses that were in the shape of a yard/square. These were social spaces where people met and interacted. The translation itself is linked to the idea of activities that would take place in the home and yard, often involving physical activity of some kind. This means the setting itself is about activity, rather than a passive setting where care is received. This is interesting in light of the importance that volunteers placed on activities that required motion, movement and an active role. In the UK ASUME study the volunteers who took part worked in many different settings and while some were involved in physical activities such as walking and dancing, there were also many examples of more passive interaction especially when people with dementia were living in residential care settings.

There were altruistic reasons expressed by both UK and Norway volunteers, but framed differently in each country. In the UK ASUME study many volunteers referred to themselves as 'caring' people and stated their motivation for volunteering as linked to altruism and a wish to give something back. In Norway there is a more modest way of framing altruism and more caution from volunteers in framing themselves in this way. The volunteers in Norway were more likely to express their own enjoyment in the activities they undertook as an Activity Friend. This may be an interesting cultural influence to explore with more data in the future to better understand the concept of altruism in the two countries.

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> Social connection and interaction are dominant motivators for volunteering in both the UK and Norway.

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