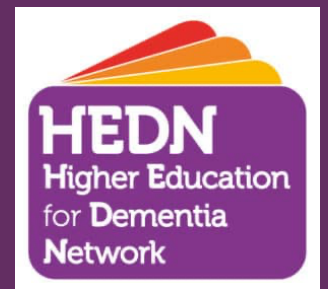


THE HIGHER EDUCATION DEMENTIA NETWORK (HEDN)

5 Year Strategy 2022-2027



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For information about HEDN visit our web-site (<https://hedn50472928.wordpress.com>)

Acknowledgements

HEDN is a network of academics in UK Higher Education Institutions who teach, research and manage courses related to dementia care at both pre and post qualifying, undergraduate and post graduate levels. More information about the network can be found on our web-site <https://hedn50472928.wordpress.com>

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Introduction

Since 2021 marked the 21st birthday of HEDN, over the last 12 months we have been developing and reviewing the strategic goals of the network. HEDN began in June 2000 when educators from a small number of HEIs and other interested parties involved in delivering the ENB (English National Board) 11 post-registration nursing course, met to discuss coverage of dementia within its content. HEDN was supported by and worked in partnership with national charity Dementia UK during this period. Since then, its remit and breadth has expanded considerably. Today, HEDN acts to provide substantive support and capacity building for its members to address challenges in the field of dementia education and contribute to the evidence base for high quality dementia education and training.

Over the next five years, our aspiration is that HEDN will continue to play a key role in ongoing dementia education research and pedagogical development within HEIs. To achieve this, the membership has developed this strategy document, which sets out a range of activities across eight areas of strategic priority. These will be delivered by the membership to meet these aims for our network.

In order to achieve our strategic goals, between 2022-2027, a series of sub-groups will collaboratively review, address and act on our strategic areas of priority. HEDN will also act to provide ongoing support, leadership and cross-institution collaboration to facilitate this engagement.

The Higher Education Dementia Network Five-Year Strategy

HEDN's aims as a network

As a network, HEDN aims to support the provision of high-quality dementia education throughout the Higher Education sector.

Background to HEDN

HEDN was established in June 2000. It was designed to act as an open forum for those with an interest in, or who are responsible for, post-registration nursing courses in dementia care in Higher Education Institutions (HEI). It has grown and developed over the last 21 years to a much wider forum. HEDN now includes academics working in higher education across the UK with a special interest in dementia education at both undergraduate and post-graduate level and across a range of subjects and vocational courses. Since our inception, we have provided a leading voice in relation to dementia education within Higher Education. Individual members and the network, have produced a range of research and publications to inform the content and delivery of dementia education and curricula in HEIs across the UK.

HEDN produced an early curriculum for dementia education (2), followed by a scoping exercise on how well HEI's were covering this content in health professional pre-registration programmes (3). In particular, this highlighted the need to include the voice of people with dementia within dementia education content and delivery (4, 5). We have continued to update this (6), and published a revised and expanded *Curriculum for Dementia Education* in 2014 (7), against which the English *Dementia Training Standards Framework* (8) is mapped.

HEDN has since published several position statements aimed at professional bodies and colleges. Our 2017 position paper (9) highlighted the importance of including reference to disease specific education and training standards, particularly those around dementia, within requirements for accreditation of pre- and post-qualifying health and social care educational provision.

HEDN's five-year strategic plan

Over recent years we have seen many trends and changes in the higher education environment and the recognition and position of dementia education within this. Across our HEIs we have seen a huge expansion in numbers of academics involved in dementia education and research and broader collaboration in these areas, not only with people living with dementia and other health and social care professionals but also with our students and learners. Yet there are some academics who are the only dementia educator or researcher in their institution, this can be potentially isolating and difficult to navigate. HEDN plays a particularly important role for many academics, in providing a supportive network of like-minded people.

Concurrently, dementia care is continually evolving as it attempts to meet the needs of an ever-growing ageing population and dementia is the leading cause of death in most Western societies. There needs to be a greater understanding of the diverse needs of people with dementia from diagnosis to end of life. Academics in HEIs must be well-prepared to take on this growing understanding through the design and delivery of our higher education provision, critically appraising professional regulatory body educational requirements and standards, working with redefined partnerships such as non-traditional health/social care settings, such as housing, and co-collaboration with our students/learners as consumers of education. The strategy also reflects the changing nature of the requirements of dementia education so that, whilst the focus remains on contexts such as social care and health, other areas including leisure, the arts, sports, tourism and business are also included. This synergises with practice and policy linked to Dementia Friendly initiatives.

In this context, HEDN has decided to develop its first five-year strategic plan, which identifies eight priority areas for work, through which we will aim to continue to take a leading role in the development of dementia education in the UK and to inform international debates, learning and practice.

Strategic area 1: Contributing to the evidence-base on the use and impact of National Dementia Education and Training Frameworks

Strategic area 2: Establishing a global presence and collaborative networks

Strategic area 3: Influencing and Conducting Pedagogical Dementia Research

Strategic area 4: Partnering with and Learning from People Affected by Dementia

Strategic area 5: Supporting the Covid-19 recovery phase

Strategic area 6: Collaborating with and learning from students and learners

Strategic area 7: Supporting those delivering dementia education in Higher Education
Institutions

Strategic area 8: Promoting Equality and Diversity in Dementia Education

Strategic area 1: Contributing to the evidence-base on the use and impact of National Dementia Education and Training Frameworks

In our 2017 position statement aimed at Professional Regulatory Bodies, HEDN called for the national knowledge and skills frameworks to be used as a basis for the design and delivery of undergraduate, postgraduate and continuing professional development programmes for all health and social care staff (9). Dementia strategies with accompanying national education frameworks for all staff and undergraduate and postgraduate education working in health and social care are present across the four nations of the UK (8, 10-12). HEDN maintains its position that national frameworks must be considered when developing curricula content. It also recognises that dementia should be covered in Higher Education curricula beyond provision within health and social care, if a society which is truly active and inclusive for people affected by dementia is to be achieved.

There has however been little direct research or evaluation carried out on the use or impact of these national education and training frameworks or their application outside of provision for those who will work in health and social care professional roles. Smith et al. (13) conducted a UK wide audit that highlighted the variability in the degree and nature of education and training across the UK using the English Dementia Training Standards framework as a benchmark. The audit suggested that some topics and subjects were underrepresented, for example advanced dementia, research and evidence-based practice, pharmacological interventions, equality and diversity and end of life care (13). HEDN supports the need for greater awareness and understanding of national frameworks to guide curricula content across professional regulatory bodies and HEIs. It also asserts the need to generate evidence on whether their application does support development of a workforce that can deliver high quality dementia care, and effective strategies for application in preparing individuals to work in the range of roles across health, social care and other sectors and fields.

HEDN's strategic goals are to:

- Ensure dementia education remains a priority for inclusion in higher education curricula
- Understand how Education and Training Frameworks and Standards are being practically implemented across HEIs
- Develop evidence-based guidance on successful application across a range of education programmes for health and social care staff
- Contribute to the evidence-base on the impact of dementia education and training frameworks and standards for the delivery of high quality dementia care
- To identify and highlight any gaps in the essential content of current Education and Training Standards and Frameworks in terms of preparing the health and social care workforce to deliver good dementia care
- Understand current practices and potential for inclusion of dementia in a broad range of non-traditional higher education curricula, (e.g. housing, leisure, tourism, sports, the arts, business etc)
- Engage with professional and regulatory bodies to promote their engagement with and support for education and training standards and frameworks

Strategic area 2: Establishing a global presence and collaborative networks

HEDN recognises that prioritising dementia education for the health and social care workforce is an area of global concern. Organisations such as Alzheimer’s Disease International (14) and WHO (1) have highlighted the critical role perceptions and understanding of dementia, including stigma play globally in preventing access to diagnosis, treatments and services for people living with dementia and those who support them. We consider that there is an essential contribution from the critical role education could play. ADI’s work (2018; 2017) highlights low levels of education and workforce readiness across many low and middle-income countries and only moderate levels in high-income nations.

HEDN recognises the role our network has to play in supporting the international effort to improve dementia education for those working in health and social care and we aim to build international connections and an international profile for the network.

HEDN’s strategic goals are to:

- Develop connections and partnerships that support the growth of high-quality dementia education internationally
- Contribute to raising the profile of curricula development and pedagogy internationally
- Contribute to and learn from approaches to dementia education research and practice from around the globe and across cultures
- Support the implementation of Education for Sustainable Development Goals 3, 4, 10 and 16 in relation to dementia education, in the UK and internationally
- Contribute to international efforts to implement action points 43, 67, 70, and 110 in the WHO Dementia Global Action Plan 2017-2025 (1) through multisectoral collaboration, educational provision and research.

Strategic area 3: Influencing and Conducting Pedagogical Dementia Research

Despite a growing body of literature on dementia education and training, this does not reflect the proliferation of dementia education and training provision over this same period. HEDN recognises there remain many gaps in the quality assurance and around understanding the impact of dementia education and training. The increased recognition of the importance of dementia education and training for the health and social care workforce has led to corresponding innovations in modes of delivery, such as the use of simulation. However, many of these pedagogical innovations require more evidence in order to draw conclusions about their efficacy and application. Likewise, there has been little consideration, for example of the efficacy of different approaches to the design and delivery of dementia education, the theoretical underpinnings of these approaches or of their impact on longer term preparedness to deliver good dementia care.

A model widely adopted in the evaluation of training and education provision is Kirkpatrick's (1984, 1979) four level 'Return on Investment' model (reaction, learning, behaviours and outcomes). Levels one and two relate to learner reactions to and perceptions of training and its impact on their knowledge and attitudes. These are the most widely investigated in the current body of research. Levels three and four refer to the extent and degree to which training impacts staff behaviour, practice change and quality of care. These are particularly challenging elements to assess, and HEDN can play a pivotal role in contributing to this evidence base. HEDN asserts that these domains of research are a priority for its members and the wider field.

HEDNs strategic goals are to

- Work with its members to generate high quality pedagogical research, published in peer reviewed journals, concerning the design and delivery of dementia education
- Carry out and support the conduct and dissemination of research, which recognises and addresses the impact, barriers to and benefits of dementia education delivered online, both synchronously and asynchronously.
- Host dementia specific education and training conferences that showcase research in this domain
- Advance our understanding of research designs and methods effective for evaluating the impact and outcomes of dementia education

Strategic area 4: Partnering with and Learning from People Affected by Dementia

HEDN believes that the involvement of people affected by dementia, that is those living with dementia and those who provide informal care and support for them (carers, supporters and other family members and friends) is an essential element of course design and student learning in dementia education. People affected by dementia are experts by experience through offering insights with their lived condition. Working alongside people affected by dementia as *active partners* in the design, delivery and evaluation of teaching and learning has the potential not only to enhance the quality and authenticity of teaching and learning, but also to challenge stigma and model best-practice in positive ways of engaging with people with dementia

HEDN recognises that there is no single approach to how people affected by dementia can best participate in teaching and learning in higher education. However, they do believe that educational providers need to work alongside people affected by dementia to develop creative, flexible and supportive ways to enable meaningful partnership work.

HEDN members have a broad and evolving experience in this area and the sharing of best practice is positively encouraged. However, we recognise there is still much to learn and do. Involvement of this nature is still not commonplace across all higher education provision. Likewise, involvement is often limited to a small number of individuals who may not reflect the broader experiences of people with dementia, particularly those from BAME communities and seldom heard groups, whose dementia is more severe or those who live in residential care.

HEDNs strategic goals are to:

- Understand how people affected by dementia are involved in higher education programmes across the UK
- Develop good practice guidance and examples of how to successfully involve people affected by dementia in the design and delivery of dementia education
- Explore, try out, evaluate and share best practice on non-traditional routes to engagement of people affected by dementia, in particular those from seldom heard groups or who experience barriers to participation via traditional routes
- To understand the benefits (and challenges) of involving people affected by dementia in educational design and delivery in higher education, from the perspective of people affected by dementia, students and educational providers.

Strategic area 5: Supporting the Covid-19 recovery phase

In its first 12 months, the global COVID-19 pandemic has had a disproportionate impact on people living with dementia, their family members and staff working across health and social care. Social distancing, the requirements to self-isolate or shield, the use of PPE and other restrictions brought about by the pandemic have changed the face of how dementia and other health and social care, may continue to be delivered for some time to come. Additionally, many HEI's have had to adapt to deliver materials online either adopting fully distance learning or blended learning approaches. Students continue to be affected by curriculum delivery moving online, and by placements being disrupted. Reduced opportunity for contact with people living with dementia may affect students' learning. For the UK Governments, health and social care providers and educational institutions, COVID-19 has been the priority and focus over this period. As we move out of COVID restrictions and back into what will become our 'new normal', HEDN recognises there is much learning to take on board and as a network we have a role to play in supporting this effort in the short, medium and long term.

HEDNs strategic goals are to:

- Understand how the COVID-19 pandemic has impacted student learning around dementia and to develop approaches to mitigate negative impacts that could be adopted across the sector.
- Contribute to local and national dementia COVID recovery plans, in particular in supporting health and social care workforce education, training and skills development.
- Play a role in the wider dementia COVID recovery within our local communities, for example through provision of education and training, exploring opportunities for students to meet needs with the local community, and engaging in research to underpin evidence-based recovery approaches.
- Support the production and dissemination of research to inform policy and practice approaches to dementia education which recognise and/or address the disproportionate impact of Covid-19 on people living with dementia

Strategic area 6: Collaborating with and learning from students and learners

Students in higher education are a diverse group, ranging from undergraduate to Doctoral level. Students can offer considerable value in co-design, both of programmes and learning activities. Evidence suggests that co design can develop shared respect, enhance satisfaction and improve personal development including intrapersonal skills (Lubicz-Nawrocka (2018). Additionally, many students may be family carers or have experience in care settings and this rich knowledge could enhance learning and teaching in dementia. The degree of involvement in curriculum design can be variable across HEIs and individual programmes. HEDN members have experience in co-design of programmes involving dementia education. HEDN recognises its work will be enhanced through greater collaboration with students who have and are accessing dementia education provision.

HEDNs strategic goals are to:

- Identify existing good practice in collaboration with students and learners in higher education dementia provision
- Promote the importance and potential benefits of drawing upon the lived experience of students as learners, carers and people.
- Encourage Higher Education Institutions to engage students as partners in enhancing their own dementia education.
- Develop an evidence-base to support future work in this area.

Strategic area 7: Supporting those delivering dementia education in Higher Education Institutions

HEDN recognises that although there has been increasing focus on curricula content as well as teaching and learning strategies for dementia education, much less explored are the characteristics, expertise, knowledge and development and support needs of those that teach the subject. HEDN asserts that understanding this is an important area for focus.

The provision of high-quality dementia education within HEIs requires highly knowledgeable and skilled educators. The professional support and development of those providing this education will be paramount in the delivery of specialised dementia education across institutions. It is therefore imperative to provide mechanisms that will enable educators to feel guided and supported in their attempts to design and deliver training and education that fulfils national curricular standards across all four countries. However, in order to achieve this, it is crucial to employ and retain staff in academic roles with the appropriate level of knowledge, experience and skills in dementia education (Collier et al., 2015).

Educators who have responsibility to design and deliver dementia education may be working in isolation within their institutions. They may have limited training in specific dementia related subjects prior to undertaking the lead for dementia within their institution. HEDN recognises it has an important role to play in this.

HEDNs strategic aims are to:

- Carry out research to discover the knowledge, skills, professional status and development needs of those running courses and lecturing/teaching in dementia in HEIs.
- Develop a programme of support to meet these ongoing needs.
- Provide a network through which educators can identify and receive mentoring and peer support.

Strategic area 8: Promoting Equality and Diversity in Dementia Education

Dementia impacts everyone in society and the dementia workforce is diverse. However, people from underserved groups (e.g. people from Black and Minority Ethnic Minority Groups, the LGBTQ community, those with Learning Disabilities and from socially disadvantaged and low socio-economic groups) are frequently under-represented in research and may have diverse and specific needs and preferences that may not be met through mainstream services or workplace practices. These needs may be neglected, or poorly considered within education on dementia. Likewise, issues specific to individuals with rarer forms of or Young Onset dementia may be neglected in current educational provision. HEDN asserts that considering equality and diversity is crucial to the provision of good dementia care and to workplaces that are supportive of all staff. It recognises that it has a role to play in promoting a proactive and critical approach to considering how issues of equality and diversity are addressed within dementia curricula in HEIs.

HEDNs strategic aims are to

- Actively support and promote the inclusion of people who identify themselves as experiencing stigma and discrimination, in the design and delivery of dementia education.
- Promote and support HEDN members in the development of teaching and learning materials to address the needs of people living with dementia from diverse and underserved groups.
- Recognise the diverse ways in which living with dementia is experienced across age, geographical, socio-economic, ethnic, religious and cultural boundaries and to support the consideration of this in members' research and practice.

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