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An online learning resource in support of the recruitment of people living with dementia and their carers to research

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Abstract

The number of people diagnosed with dementia is increasing globally, however it is estimated that only 2% are engaged in dementia research. In part, this may be due to a lack of confidence on the part of health and social care professionals to discuss research opportunities. Discussing research is necessary as part of a holistic approach to care.

To support conversations about research, an interactive e-learning course was developed, comprising four modules to increase Admiral Nurses, specialist dementia nurses', confidence to discuss research opportunities and so participation with people with dementia and their family carers. An evaluation of the course sought to understand if such a course increased Admiral Nurses' confidence in discussing research opportunities with families affected by dementia to promote their registration with the Join Dementia Register.

We used Kirkpatrick's Model to evaluate the pilot of the e-learning course, which consists of four levels: reaction (level 1), learning (level 2), change to behaviour (level 3) and impact (level 4), and embedded both quantitative and qualitative approaches to the evaluation.

Twenty-one Admiral Nurses completed all four modules of the course. Their reaction (level 1) to the course was evaluated as positive using free comments on the course content and format. Confidence was rated pre and post course. Using Wilcoxon signed-rank test we found statistical significance ($z = -4.01$, $p < .001$) in self-rated confidence to undertake conversations about research post course than before. Change to behaviour (level 3) and impact (level 4) show promise but would require further, longitudinal consideration.

The pilot evaluation showed positive outcomes, particularly in increasing Admiral Nurses' confidence to discuss research with families affected by dementia. Using scenarios and case studies to enhance clinical practice and patient outcomes, emphasised the importance of self-confidence in professional interventions. This approach could be adapted to other health and care disciplines.

Introduction

Dementia

An estimated 950,000 people live with dementia in the United Kingdom (Wittenberg et al., 2019) who are supported by approximately 700,000 family carers (Carers UK., 2021). Families affected by dementia have a range of post-diagnostic needs, some of which may be complex, which have been a policy focus on dementia in England and Wales for over a decade (DHSE, 2009, NICE, 2018). Admiral Nurses are specialists in dementia care and offer post-diagnostic support for families affected by dementia, such as through facilitating practical approaches for living with dementia, offering emotional support to help build resilience and develop coping strategies. They also support best practices among generalist practitioners through education and leadership (Harrison Denning et al., 2019). Admiral Nurses are supported in their practice development and clinical supervision by the charity, Dementia UK, who use Blackboard™ as their educational and learning platform. One of the many aspects of the Admiral Nurses' professional development is in developing their research mindedness, sometimes referred to as research minded practitioner (Liedgren, 2020).

Research and dementia

Awareness of dementia in the general population continues to rise since this being made a priority in the National Dementia Strategy (DHSE, 2009), but there remain key pockets of misunderstanding of dementia which impacts on families affected by dementia's understanding of and poor access to participation in dementia research (Alzheimer's Research UK (ARUK) 2023). Conducting research to develop and advance new interventions is essential for treating symptoms, modifying disease progression, understanding biomarkers, and improving dementia care practices with the aim of enhancing the quality of life of the person with dementia, as well as their family carers. Involvement and engagement in research play a huge part in this with health and social care professionals having a pivotal role in discussing research participation with them as part of the recruitment process so it is

essential that health and social care professionals in providing holistic care, have the necessary knowledge and skills to discuss opportunities to engage in research. However, some may find this form of conversation difficult to hold, perhaps due to a lack of research mindedness (Pepper, et al., 2024). This may be due to their own lack of knowledge and skills in understanding what the research is about to then be able to confidently answer any early questions and from there to seek interest in a person's participation (Lepore, et al., 2017; Lee, et al., 2022).

To address the challenge in matching potential participants to dementia research studies, the Join Dementia Research (JDR) programme was established by NIHR in 2015 (JDR, 2025). A register aimed at matching a person with dementia or their family carer or supporter to dementia research studies, whether on-line, nationally or in their local area and also seek to understand the referral source of the person registering their interest. However, despite such a national initiative, participation of people affected by dementia in research remains limited, and recruitment to studies still a challenge with only 2% of people with a dementia diagnosis in the UK are signed up to hear about research (UKDRI, 2024), estimated to be 100 times less than recruited to cancer research (ARUK, 2022). This may be multifactorial as to why this might be so, such as a lack of capacity to consent for some people with dementia but also may be due to health and social care professionals' lacking research mindedness and so confidence in discussing research opportunities.

Research-mindedness

Researchers (Liedgren, 2020; McBeath & Austin, 2015; Daniels et al., 2021) have suggested the concept of research-mindedness in health and care practitioners has developed from the field of knowledge management. Research-minded practitioners are interested in knowledge and research as drivers for development, and are characterised by their curiosity, critical reflection and capacity for critical thinking (McBeath & Austin, 2015). In the context of Admiral Nursing, research-mindedness can be seen as spanning a continuum in their practice, at one end embracing the ability to access research literature relevant to their practice and patient population, the ability to critique

such literature, and to apply research evidence to inform their practice (Pepper et al., 2024). At the other end of this continuum the level of research-mindedness might embrace leading and conducting their own research (Pepper et al., 2024), as exemplified in the Nursing and Midwifery Council (NMC) pillars of advanced practice (NMC 2025). Pepper and colleagues, in a survey of Admiral Nurses, found many barriers to their understanding of research and research-mindedness, as well as their educational and support needs to better engage in research related activities (Pepper et al., 2024). Further to the survey, Pepper and colleagues considered how an Admiral Nurse's research-mindedness may impact on their ability to promote engagement in research for the families they support. Their findings were consistent with similar research in other nursing roles (McMaster et al., 2013). These factors were considered central to be able to confidently discuss research opportunities with the families they clinically support.

Recruitment of research participants

Recruitment of people with dementia into research studies is essential in order provide evidence for effective care and treatment, however, recruitment is known to be difficult for this population (Davis & Bekker, 2022). Davis and Bekker, in their integrative review to synthesize the evidence surrounding best practices for recruiting older adults with dementia into research, found barriers to recruitment of this population included non-targeted recruitment methods, gatekeepers, and mistrust. Gatekeeping in the recruitment of people with dementia and their family carers into research studies may imply the clinician actively creating the barrier. However, Davis and Bekker (2022) report that in addition to professionals arguing a lack of time to refer patients to research studies, professionals also had concerns about their confidence and discomfort in discussing research studies with potential participants.

Developing an educational resource to support recruitment

As part of a suite of educational resources in research and research-mindedness, we thus aimed to develop an e-learning course to enable Admiral Nurses to hold *confident conversations* with people with dementia and their family carers about research opportunities and participation through the Join Dementia Research (JDR) register.

E-Learning

E-learning is an umbrella term used to encompass various concepts and learning-related technologies, such as distance, digital, electronic, on-line, and mobile learning (Prosen, et al., 2022). E-learning offers both limitations and advantages over the more traditional, face to face, classroom methods of education. Some researchers have sought to identify the limitations and advantages to e-learning in nurse education. Oliveira, Penedo and Pereira (2018), using an exploratory case study approach compared e-learning to traditional teaching methods. They identified e-learning as socially isolating for learners, perhaps generating a sense of loneliness, placing high demand on their time management and the risks of poor or unstable internet connections a challenge largely borne by the learner. Among the advantages, are the lack of dependence on a specific time and space for delivery, greater individualisation of learning materials inside an interactive environment, cost effectiveness, flexibility and transferability, consistency in delivery, greater participant sign up and involvement (Fidalgo, et al., 2020; Mlinar Reljić, et al., 2023). Whilst the advantages seem to outweigh the limitations, careful consideration and management may be required to reduce these, even more so since Covid-19 and the increased use of the e-learning format (Zalat, et al., 2021).

Methods

This pilot evaluation did not require ethical approval as it was classified as service improvement rather than research. The authors assessed this using the HRA decision tool. The evaluation aimed to

identify improvements within Admiral Nursing specifically, without seeking to provide generalisable or transferable findings beyond this context.

Evaluation questions

Two overarching questions guided this evaluation: 1) Does the on-line course, 'Confident Conversations' increase Admiral Nurses' confidence in discussing research opportunities with families affected by dementia? 2) Does completion of the course increase Admiral Nurse referrals to the JDR register from families affected by dementia they support?

Developing the course curriculum

To begin the development of the course content, the authors collaborated across Dementia UK and Join Dementia Research (JDR) of the National Institute of Health Research (NIHR) programme, to create draft content, including the positioning of interactive elements, illustrative video clips, reflective practice. Each module was scripted and filmed using the authors as narrators and educators for their respective sections. This gave authenticity to the messages contained in the course, for example Admiral Nurses and Dementia UK Research Team delivered the sections relating to Admiral Nurse practice and JDR representatives to inform about the purpose of the JDR register. We wanted Admiral Nurses undertaking the course to experience it being bespoke to their expressed learning needs, as identified in a recent research mindedness survey (Pepper et al., 2024).

The course consisted of four modules which included: background and rationale to the course, the value of research to families affected by dementia, aspects of professional research mindedness, the work of JDR and the ways to sign up to its register, through to animated scenarios to model practice and to engage research participation (see table 1). For each module, a range of education approaches were used to keep the learner engaged, including taught written content, videos, interactive elements, quizzes and reflective practice (Unmi, et al., 2024) using a system called Padlet™, a digital education communication platform. In a systematic review of e-learning in health

profession education, Cook and colleagues (2010) identified the value of this range of teaching strategies and their positive impact on learning outcomes. To enhance the e-learning course further, we provided a workbook to reflect on participants' understanding outside of the modules and which could be used towards their professional revalidation (NMC, 2021).

Once we had the written content for each module, a learning content designer within NIHR began building the e-learning course within the *NIHR Learn* learning system (NHS HRA, 2024). Each module was worked on one by one and then sent to authors for their review and feedback before we moved onto building the content for the next module. This allowed us to fully complete each module to a standard that everyone was happy with and incorporated all feedback before we moved onto the next module.

We trialled the course with seven Admiral Nurses for its learning outcomes, engagement, accessibility, and functionality. From their comments, we worked iteratively on the development and refinement of the course. One issue raised in the development phase was the need for ease of access to the NIHR Learn platform where the course was located, so a link to the e-learning module was created in Blackboard™, and a PDF guide was developed. Data from the seven Admiral Nurses engaged in the trial was not included in the final results but more that their feedback was used to test its feasibility and acceptability.

Table 1 approximately here

Using the Kirkpatrick® Model (Kirkpatrick & Kirkpatrick, 2022) this pilot evaluation aimed to develop an e-learning course to increase Admiral Nurses confidence to discuss research opportunities with families affected by dementia. The purpose was to develop, pilot and evaluate an on-line course to develop research mindedness in Admiral Nurses and increase their confidence in discussing research

participation with the families affected by dementia that they support. The Kirkpatrick® Model is widely used to evaluate both formal or informal learning and any style of training and consists of four levels (see figure 1):

Level 1 – (Reaction) engagement with the training

Level 1 (reaction) should measure participants' engagement in the learning experience in addition to the overall and accumulative number of participants of a course. Often evaluators of an educational intervention measure the number of attendees of a course as a key performance indicator of programme success. However, Kirkpatrick and Kirkpatrick (2022) argue that measuring engagement which focuses on the quality of experience while involved in programme activities, rather than numbers of attendees, plays a more significant role in the overall quality of the experience. To understand participants reaction to the course we consulted with Admiral Nurses during the development stage and then Admiral Nurses that subsequently undertook the course by collecting anonymised, free text comments on their perceptions and experiences at the end of each of the four modules.

Level 2 – (Learning) confidence pre- and post-course

This level, identified as learning, seeks to evaluate the extent to which learning has been achieved (Kirkpatrick & Kirkpatrick, 2022). In this pilot evaluation we aimed the learning to show an increase in the confidence of the participants to hold discussions about research participation with families affected by dementia. We asked participants to rate their confidence at two points in time; pre and post course, using a five-point Likert scale (1 = no confidence to 5 = high confidence).

Level 3 – (Change to behaviour) How Admiral Nurse perceived use of the new knowledge

In levels 3 we sought to understand how the nurses perceived their new knowledge would impact on their behaviours and practice relating to research discussions with families affected by dementia,

going forward. To achieve this, we embedded opportunities to reflect on each of the modules as they were completed. The Admiral Nurses were invited to offer free text comments as examples of knowledge to practice intentions.

Level 4 – (Impact) Increase in registrations with JDR

The JDR register collects data on the referral source for any person registering an interest in the register. One of the categories for referral source is 'Admiral Nurse'. We sought to explore if there was an incremental increase in baseline data of referrals from Admiral Nurses as a result of completion of the course in the three months after course completion. As this was an evaluation of the piloting of the course, further study for impact, beyond reflecting an increase of referrals to JDR noting an Admiral Nurse source and consideration of other influencing factors will be part of future study.

Figure 1 approximately here

Results

We recruited 21 Admiral Nurses to the course advertising it via the internal Admiral Nurse Newsletter and through their on-line professional development learning platform, Blackboard™. The course opened in October 2024 with the last of the 21 participants completing in January 2025.

Participation required no collection of demographic data, other than being an Admiral Nurse, and all confidence scores and free comments were anonymous.

Using Kirkpatrick and Kirkpatrick's (2022) four levels, we report the findings:

- 1) understand learner's reaction to and satisfaction with the course
- 2) measure their level of confidence to hold research conversations, pre and post the course

- 3) seek to understand any perceived changes in behavior or intention in practice following the course (discussing research opportunities and registration with JDR)
- 4) increased number of JDR registrations attributable to Admiral Nurses.

Reaction

The reaction of Admiral Nurses, both during the testing phase of the course and in the first cohort, were positive. Overall, feedback was positive with appreciation of the curriculum content and the range of different learning components, including videos, interactivity and opportunities for reflection. Admiral Nurses reported a smooth user experience and valued undertaking the learning at their own pace, pausing as wished and enabling progress to be saved.

The first module in the course informed the participant about dementia research and the wide variety of studies that families could engage in, but also in the benefits individuals could derive.

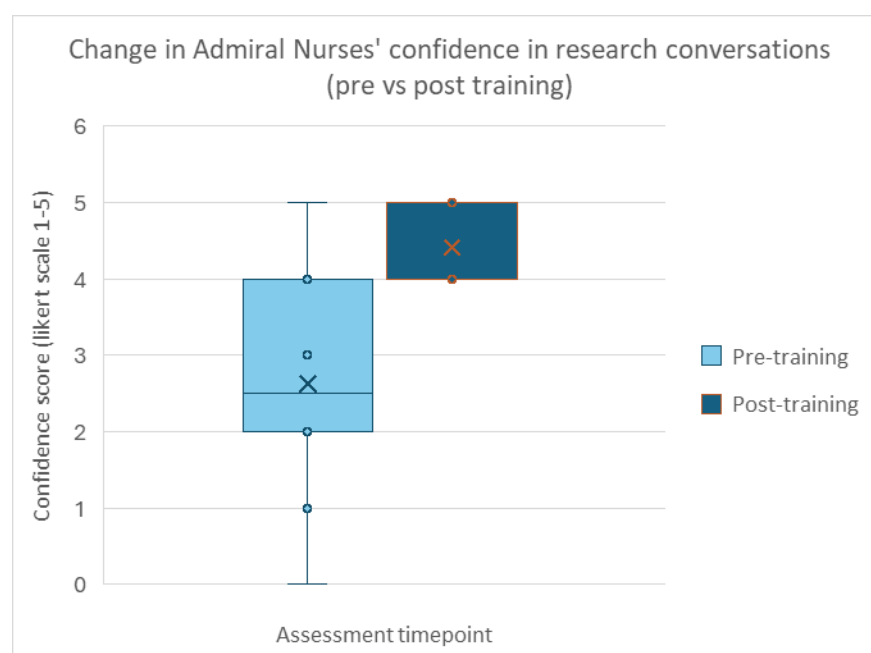
Many Admiral Nurses found the benefits to participating in research and the dispelling of myths held about research and dementia useful in guiding future conversations with families affected by dementia: *"I have a much more focused understanding of the advantages of research"*. Some participants perceived people's awareness of research opportunities being largely limited to pharmaceutical trials and felt their greater knowledge of the range of studies and research methodologies as being a useful myth to dispel in their future discussions: *"... [there are] misconceptions about health research in general ... research being primarily drug trials"*. Similarly, one participant's reaction to this new knowledge was that the media had a large part to play in sustaining this myth in families affected by dementia: *"... people ... associate research with medication due to the media exposure"*. Another participant's early reaction to now understanding the breadth of dementia research was: *"[a point] that struck me the most was [there is the myth] that research is predominantly about finding a cure [for dementia]"*.

Learning

Participants rated their confidence in holding discussions with families affected by dementia about research participation both before and after the course (Level 2). All participants provided ratings at

both time points. Confidence scores were collected pre- and post-training. Prior to training, the 20 participants' scores ranged from 1 to 5 (the maximum range), with a mean of 2.7. Post-training scores ranged from 4 to 5, with a mean of 4.6, representing an average increase of 1.9 points. A Wilcoxon signed-rank test indicated that this increase was statistically significant ($z = -4.01$, $p < .001$), demonstrating that Admiral Nurses' self-rated confidence to undertake conversations about research was significantly higher after completing the on-line course than before (see figure 2).

Figure 2: Box plot illustrating the change in Admiral Nurses' confidence in discussing dementia research before and after training.



Change to behaviour

Given the nature of this pilot evaluation we did not measure longitudinal behavioural changes in Admiral Nurse practice. However, additional to the comments received of Admiral Nurses during the development stage, we sought to understand how participants of the pilot *perceived* their new knowledge would impact on their behaviours and practice relating to research discussions with families affected by dementia, going forward. At the end of each of the four modules we invited free text comments and give examples of how they felt their new knowledge would translate into practice intentions. The new knowledge gained through the course enabled participants to now feel better equipped to undertake discussions: “... [I now know so much more].. *I just was not sure how to*

articulate [research studies] ...”. The animated scenarios were useful for several participant’s in offering a range of problem-solving approaches and personalising discussions to the individual and type of research: “ ... *I’d avoid jargon, challenging or insensitive words and phrases. Would aim to pitch the conversation at an appropriate level both for the person with the diagnosis and their family*”. Similarly, another participant acknowledged the need to go at an individual’s pace: “*The language I would use would be sensitive to the situation ... using a curious approach ... have you ever considered? I would not go straight in*”. At the end of the fourth and final module one participant felt their new knowledge gave them a greater understanding of the value of dementia research and take this into their future discuss with families affected by dementia: “*I have a much more focused understanding of the advantages of research ... I just was not sure how to articulate these ...* ”.

Impact

Before the Confident Conversations course was launched, from September 2023 - August 2024 (one full year), there had been 34 individuals registering with JDR that attributed the referral source as an Admiral Nurse. In the six-month period from September 2024 (start of the course pilot) to February 2025 there have been 26 registrations that attribute their referral source as an Admiral Nurse. Whilst these numbers are small, they show a small increase on the previous year and the possibility of an interesting trend. However, at this stage, the numbers are too small to draw any meaningful statistical conclusions, a full one-year follow-up on this data will be undertaken at a later date.

Discussion

This pilot evaluation was guided by two overarching questions to seek to know if undertaking an on-line course could improve confidence in discussing research opportunities and increase Admiral Nurse referrals to the JDR register from families affected by dementia they support. We have demonstrated positive outcomes using the education evaluation Kirkpatrick and Kirkpatrick Model (2022), but especially so in increasing Admiral Nurses’ confidence (level 2) to discuss research and research opportunities with families affected by dementia. Confidence is considered an important

variable in practice as nurses with higher levels of confidence are likely to undertake safer and successful interventions (Almeida et al., 2019). However, self-confidence is also important as it acknowledges the nurses' individual abilities and emotions (Kukulu et al., 2013). Furthermore, it supports the belief of being successful and to believe in themselves and their abilities in a particular situation to successfully undertake conversations about research.

The course set the context, i.e. research participation in dementia, using a scenario, case study approach. Presenting and reviewing case studies in nurse education offers ideas on how an intervention can improve their clinical practice and so patient outcomes (Seshan et al., 2021). Case studies can also generate a deeper understanding of complexities encountered in a real-life clinical context within the safety of simulation. Simulated patient scenario's using videos enabled the Admiral Nurses to work with the 'patient' as autonomous professionals making their own decisions (Koukourikos et al., 2021).

Strengths and Limitations

This small pilot evaluation of an educational intervention to support Admiral Nurses to have confidence in discussing research participation with families affected by dementia has demonstrated promise. Confident Conversations as an approach to increase professional confidence in holding such discussions could easily be adapted to other health and care disciplines and professional groups.

Whilst data collected in evidence of impact (level 4) shows promise, this small pilot did not demonstrate a significant upward shift in Admiral Nurse referrals to JDR given the small numbers of the pilot and the difficulty in attributing any increase as an impact of this intervention. However, given the success of the course in improving confidence of Admiral Nurses, it is anticipated that this number will increase incrementally as more Admiral Nurses embark on this learning. Similarly, whilst the Admiral Nurses indicated an increased confidence to discuss research with families affected by dementia, this does not mean that people affected by dementia will go onto register on JDR or indeed participate in research.

Conclusion

It is important for people diagnosed with dementia and their family carers to have the opportunity to engage in dementia related research. To do so requires health and social care professionals to confidently discuss research opportunities with them. Providing education to equip health and social care professionals with the knowledge and skills about research increases their confidence to hold these conversations. Further course evaluation is required to understand if Admiral Nurses' intention to hold conversations with families affected by dementia increases registration on the Join Dementia Research register. This course, with minimal adaption could be relevant to the wider nurse population or other specialist nurses and may be of particular relevance in services where dementia is diagnosed.

Conflicts of Interest

The authors declare no conflict of interest

Author contributions

Conceptualisation of pilot, KHD and JM. Methodology, KHD, EW, AP, JM. Formal Analysis, KHD, MW. Validation of analysis, EW, JM, AP. Data Curation, JM. Writing – Original Draft Preparation, KHD.; Review & Editing, KHD, EW, MW, AP, JM.

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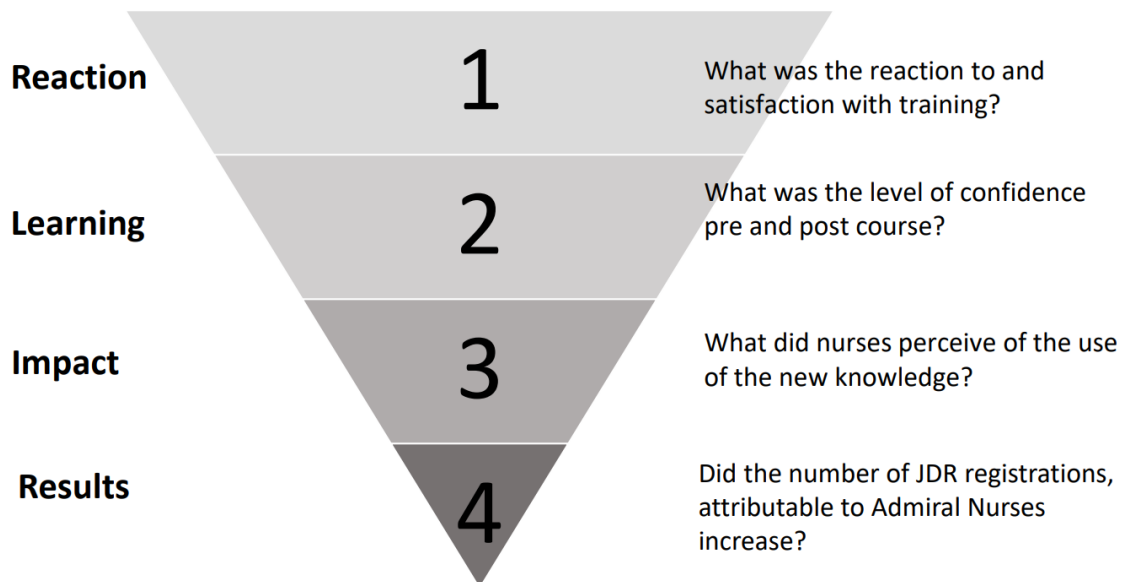
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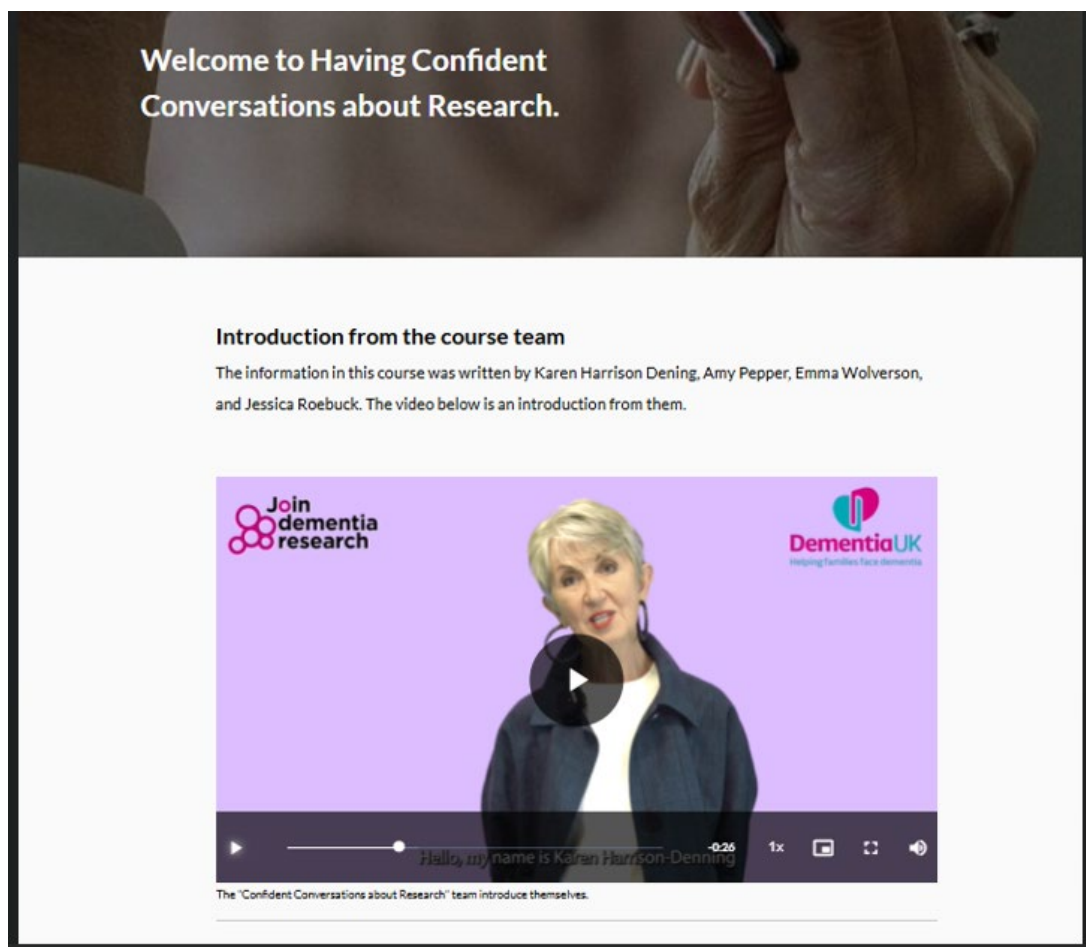
Table 1: Course curriculum

Module	Content
1	Indicative content and expected learning outcomes. Background and rationale for the course. Importance to the role of Admiral Nursing. Reflections on current practice and new learning.
2	Introduction to research. The importance of research in dementia. Overview of the types of research. Statistics on dementia research. Misconceptions about research. Reflection on practice and new learning.
3	What is the Join Dementia Research (JDR) register. Who can register. How to support people to register and the sign-up process. The types of research JDR supports. Cameo's of people with dementia and family carers registered with JDR and the perceived benefits. Reflection on practice and new learning.
4	Animated case scenarios to consider a range of conversations about research opportunities. Reflection on practice and new learning.

Figure 1. Kirkpatrick's Model of training evaluation (adapted from Kirkpatrick & Kirkpatrick 2022)



Screen shot images to be interspersed throughout article

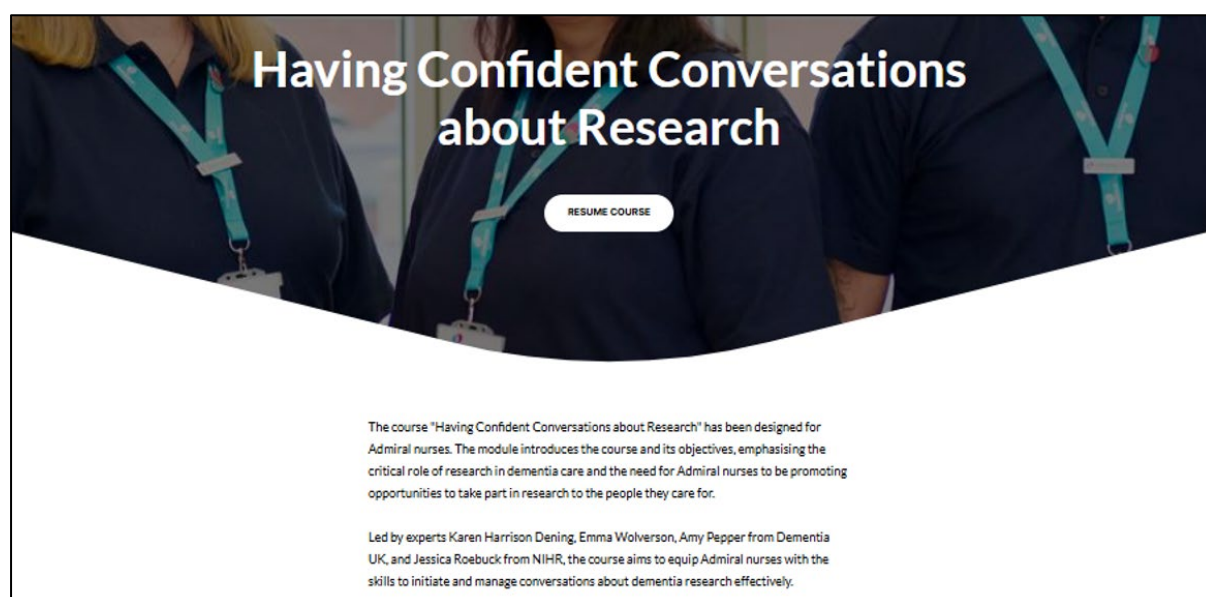


Welcome to Having Confident Conversations about Research.

Introduction from the course team

The information in this course was written by Karen Harrison Denning, Amy Pepper, Emma Wolverson, and Jessica Roebuck. The video below is an introduction from them.

The video player shows a woman with short blonde hair, Karen Harrison Denning, speaking. The background is purple. Logos for 'Join dementia research' and 'DementiaUK' are visible. A play button is centered over the video. The video title 'Halo, my name is Karen Harrison-Denning' is at the bottom. Below the video, a caption reads: 'The "Confident Conversations about Research" team introduce themselves.'



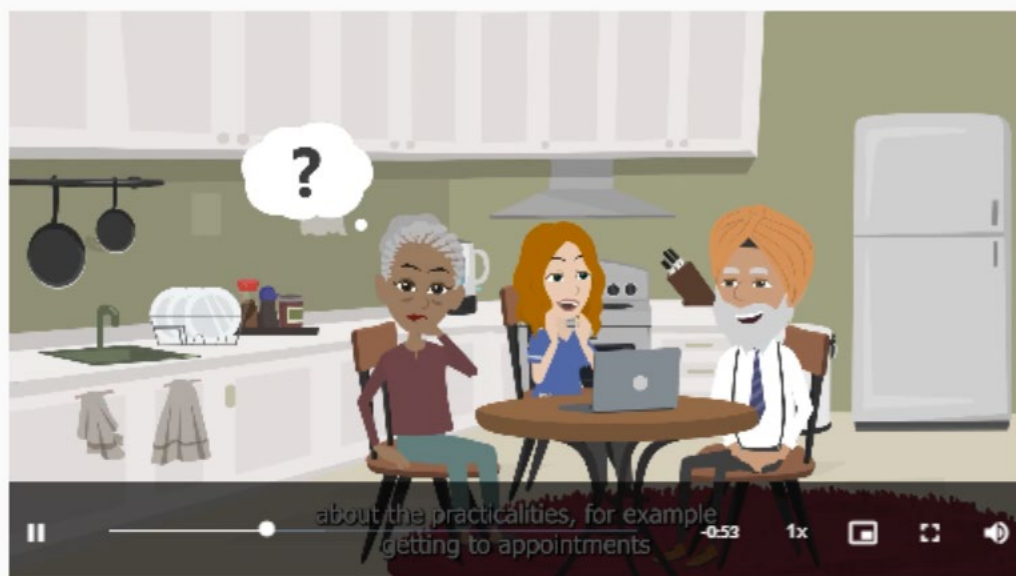
Having Confident Conversations about Research

[RESUME COURSE](#)

The course "Having Confident Conversations about Research" has been designed for Admiral nurses. The module introduces the course and its objectives, emphasising the critical role of research in dementia care and the need for Admiral nurses to be promoting opportunities to take part in research to the people they care for.

Led by experts Karen Harrison Denning, Emma Wolverson, Amy Pepper from Dementia UK, and Jessica Roebuck from NIHR, the course aims to equip Admiral nurses with the skills to initiate and manage conversations about dementia research effectively.

Scenario 2: A person with dementia is interested in becoming involved, but the carer is not (or vice versa)



Charlie Jones talks about situations where the carer or family member isn't sure that they want the person they care for to get involved in research.

There are many different types of studies registered on Join Dementia Research. From studies looking into new medication to treat dementia, to online surveys that someone can complete from the comfort of their own home.

The most common studies people match tend to be online studies that might involve completing a questionnaire or completing an online activity or memory test. The less common ones people match to are clinical trials that will involve trialling new drugs, but we do have plenty of these available on Join Dementia Research for the people they are suitable for.

The interactive picture below tells you about the different types of studies available to people through Join Dementia Research and what they might involve.

Click on the numbers to reveal more information.

