

# Veterans Living with Dementia

## Stakeholder Event Report



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## **Contents**

<b>Introduction.....</b>	<b>p3</b>
<i>Background.....</i>	<i>p3</i>
<i>Purpose.....</i>	<i>p3</i>
<i>Methods.....</i>	<i>p3</i>
<i>Attendance.....</i>	<i>p5</i>
<i>Event Programme.....</i>	<i>p6</i>
<i>Data collected.....</i>	<i>p7</i>
<b>Define.....</b>	<b>p7</b>
<b>Discover.....</b>	<b>p9</b>
<b>Dream.....</b>	<b>p10</b>
<b>Design.....</b>	<b>p11</b>
<b>Deliver.....</b>	<b>p12</b>
<b>Conclusion.....</b>	<b>p12</b>
<b>Collaborator List.....</b>	<b>p13</b>

## **Introduction:**

### **Background:**

The Ageing and Dementia Research Centre (ADRC) at Bournemouth University specialises in dementia and dementia-related research and received funding from Dementia Research UK in 2023/4 to initiate a project with military veterans as an underserved population in the dementia community. The project was developed to explore the experiences of veterans living with dementia using a collaborative approach throughout a series of creative workshops, involving initial conversations with veterans about the project ideas through to creating a documentary style short film which puts the voices of the veterans at the forefront to tell their stories. The workshops involved various activities including cooking, drumming, instant theatre, art and singing. Throughout the workshops, the research team participated in activities alongside veterans and their carers whilst also having conversations about their lived experiences and inviting them to share their stories.

### **Purpose:**

After the workshops, we held a stakeholder event. The purpose of this event was to create an inclusive shared space with stakeholders, service providers, researchers and veterans living with dementia and their carers to share the project outcomes, reflect and discuss further steps. The day aimed to understand the barriers and enablers for the wellbeing of veterans living with dementia and their carers as well as identifying service development and research priorities.

### **Methods:**

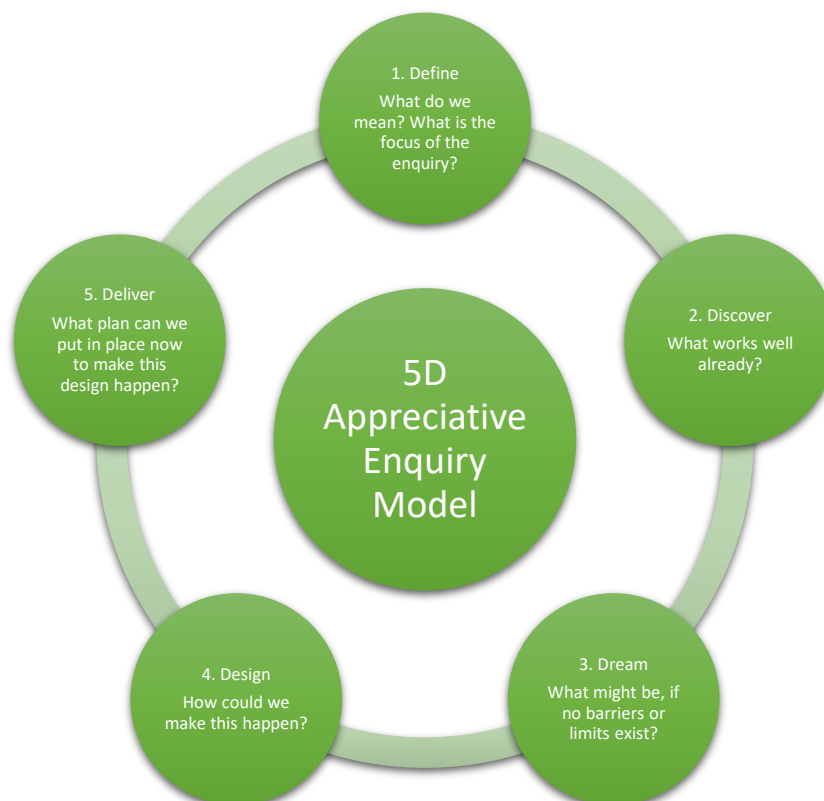
The stakeholder event was co-led by Dr Michele Board (Principal Investigator), Rebecca Dew (Research Assistant) and Kate Jupp (PIER Officer in the BU Public Involvement and Education Research Partnership), structured around an appreciative enquiry model approach. Described as “an ongoing co-construction of reality” by its founders (Cooperrider & Srivastva, 2013)<sup>1</sup>. The appreciative enquiry approach aims to bring together current reality with a realisation of the possible. The day was structured around a five-stage 5D Appreciative Inquiry model process:

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<sup>1</sup> Cooperrider, D. L., & Srivastva, S. (2013). A Contemporary Commentary on Appreciative Inquiry in Organizational Life Appreciative Inquiry in Organizational Life ☆ Cooperrider, D. and Srivastva, S.(1987). Appreciative inquiry in organizational life. In R. Woodman and W. Pasmore (Eds.), Research in organizational change and development, Vol. 1, pp. 129–169. In *Organizational generativity: The appreciative inquiry summit and a scholarship of transformation* (Vol. 4, pp. 3-67). Emerald Group Publishing Limited. [https://doi.org/10.1108/S1475-9152\(2013\)0000004001](https://doi.org/10.1108/S1475-9152(2013)0000004001)

**Define, Discover, Dream, Design and Deliver** - for further information, see:

<https://i2insights.org/2024/01/16/using-appreciative-inquiry/>.



The session's activities were founded on the principles of co-production, which acknowledges that people with 'lived experience' are often best placed to advise on what support and services could make a positive difference to their lives.<sup>2</sup> Using values of co-production, the project focused on maintaining a person-centred perspective and fostered a collaborative approach.

It was very important to us to continue using this approach, where participants and researchers were seen as equals throughout the workshops and stakeholder event, collaborating as equal partners for equal benefit.

We welcomed a range of attendees from various backgrounds including research collaborators, senior nursing staff, locality managers of dementia care, charitable organisations, civil service, to veterans and carers with lived experience and personal interest. Therefore, activities were designed on "World Café" methodology based on the belief that 'we are wiser together' and that the future can be shaped 'through conversations that matter' (citation from: [World Cafe |](#)

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<sup>2</sup> [NHS England » Co-production](#)

[Involve](#)). This approach is a ‘powerful social technology for engaging people in conversations that matter’ and is a popular approach for hosting large group dialogue, for further information see: [World Cafe Method | The World Cafe](#).

Positive feedback was received from various stakeholders about the event:

**Louise, carer for Bruce, a veteran living with dementia:**

*“I want to know how much help we can get for him, where we can find it and who we need to talk to because, as we were saying, we slipped through the net a bit because he was diagnosed in Covid times.*

*It’s been good to talk to everyone. They need help, they need services, they need to know where to go, and I need to know who’s going to help me.”*

**Ashleigh Boreham, Deputy Chief Officer for Strategy and Innovation, NHS Dorset:**

*“It’s also a great opportunity to network and join people up. And learn from the veterans’ lived experience, which is so important. And also the lived experience of the carer for the veteran – there’s never a veteran on their own, there is a whole unit of family support, partners, that are connected around that veteran and when the veteran has dementia they are there to support the veteran like the veteran supported society and hold them up.”*

**Attendance:**

We welcomed 20 attendees to the event from organisations including the Royal British Legion, Help for Heroes, Integrated Care Board, Department for Work and Pensions, Sanbu, Dorset County Hospital NHS Foundation Trust, Age UK, collaborators, and veterans and carers.

## **Event Programme:**

The event programme was developed based on the principles of the 5D appreciative enquiry model as follows:

<b>Time</b>	<b>Activity</b>
<b>10.30</b>	<b>Arrival and registration</b>
<b>11:00</b>	<b>Welcome</b> – introducing the event plan and the 5D model
<b>11.05</b>	Table introductions, who you are and why you are here today
<b>11.10 – 11.30</b>	<b>Define</b> – introducing the topic, showing the film and immediate group reflections
<b>11.30 – 11.55</b>	<b>Discover</b> – from watching the film ‘We discovered...’ Captured per table
<b>5 mins</b>	<b>Discover Sharing</b> – ask each table to share 2 Discovers with the group
<b>12.00-12.25</b>	<b>Dream</b> – What is the best it could be for Veterans living with dementia? Captured per table
<b>5 mins</b>	<b>Dream Sharing</b> – ask each table to share 2 Dreams with the group
<b>12.30 – 1.10</b>	<b>LUNCH</b>
<b>1.10 – 1.15</b>	<b>Re group, re-cap what we have done so far and reminder of rest of the plan.</b>
<b>1.15 – 1.40</b>	<b>Design</b> – What can we take from the dream and make it happen, what is achievable?
<b>5 mins</b>	<b>Design Sharing</b> – ask each table to share 2 designs with the group
<b>1.45 – 2.10</b>	<b>Deliver</b> – next steps what are we going to do now, collectively, and individually?
<b>15 mins</b>	<b>Deliver</b> – sharing a bit different for deliver
<b>2:25</b>	<b>Individual Pledge cards</b> – each person was asked to fill out a pledge card of something they would like to do (to raise awareness... etc)
<b>2:30</b>	<b>Park</b> – sharing additional thoughts
<b>2.35</b>	<b>Thank you and final opportunities to network</b>
<b>2:45</b>	<b>Finish</b>

## **Data collected**

Attendees were invited to share their thoughts and comments throughout the day and all feedback was collected on large sheets shared per table. This included the four sections of Discover, Dream, Design, Deliver, as well as “Park” sheets which allowed participants to share additional thoughts they felt were relevant/important but might not fit under the topic heading, or were thoughts they wanted to return to. These sheets were then collected and data summarised under the following subsections.

## **Define - What do we mean? What is the focus of the enquiry?**

To define our topic, we began introducing the project we had been collaborating on with veterans and their carers. We outlined why this was such an important group to work with so that we can identify what research needs to be undertaken in the future. For example, research suggests there are links between Traumatic Brain Injury and PTSD to dementia (Raza et al., 2021), which is poignant for veterans who have increased exposure to experiences associated with this. Further research has also suggested there may be links between traumatic brain injury and young on-set diagnoses (Nordström et al., 2014). We explained to delegates that our workshops project set out to discover what the experiences are of veterans who are living with dementia and explore their unique needs.

Throughout the workshops, we explained that we had filmed the activities, as well as interviews with participating veterans and carers, to capture these outcomes. We then captured this in 10-minute film that was then shown to all attendees for them to view some of the activities and hear the stories of participating veterans and carers to bring their voices to the forefront of the day.

To access the film, please scan the QR code or follow this link:  
<https://www.youtube.com/watch?v=D7eb0jSTGBs>





Image 1 (above): Workshop 6 – Cookery session enjoying the bread rolls we made together with soup



Image 2 (above): Workshop 3 – After our Instant Theatre session had finished



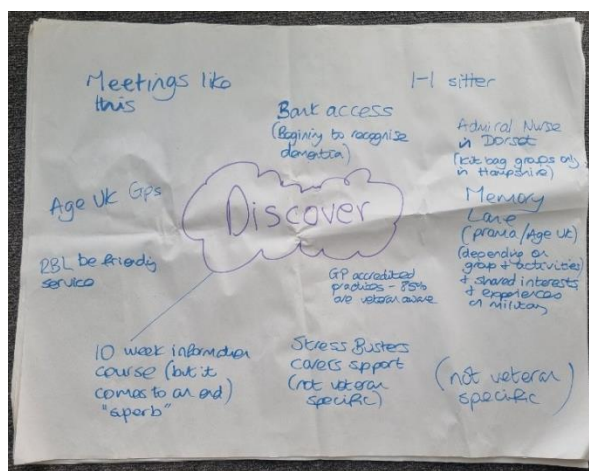
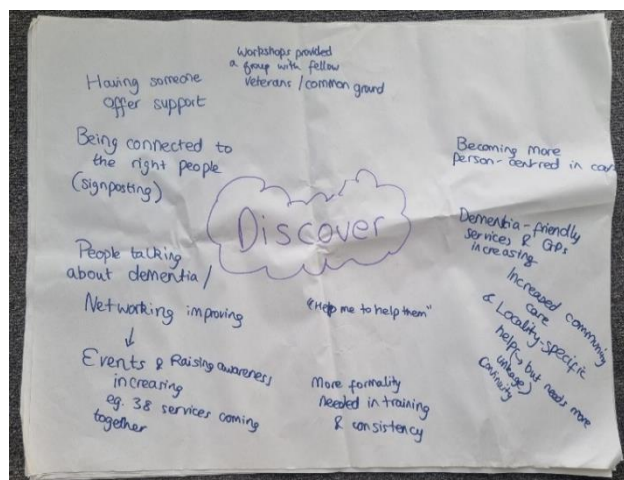
Image 3 (above): Stakeholder event – Gathering ideas



## Discover – What works well already?

Discussions were then based around the “Discovery” aspect which involved conversations around what works well either in that person’s organisation or experiences. We discovered that more places, including GPs and banks, were beginning to recognise dementia and more places are becoming “dementia friendly”. People working in healthcare generally were also becoming more person-centred in their approach to care. One attendee shared that community care is increasing and locality-specific help is improving, however, more linkage for continuity of care was needed. People are talking about dementia more than before, networks are improving and there are more events taking place increasing awareness.

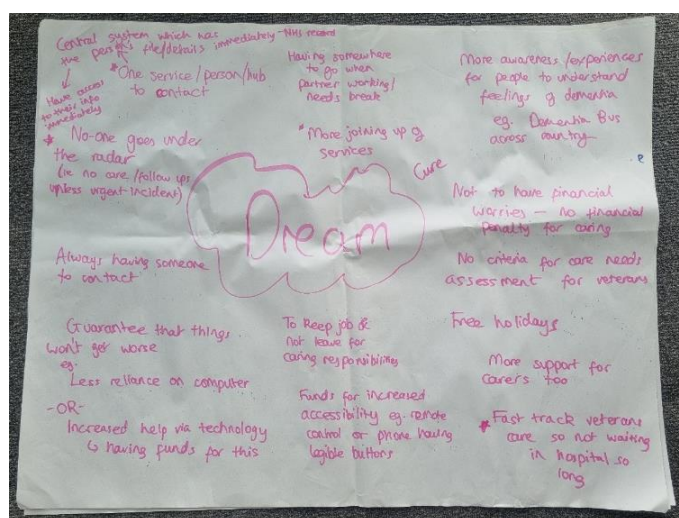
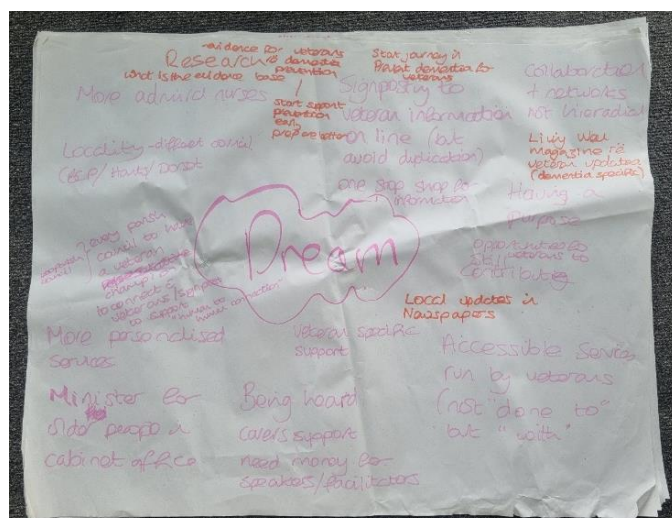
However, there is still ambiguity around the awareness of veterans with dementia and veteran-specific help. The Royal British Legion’s befriending service was discussed as a positive initiative to help veterans, as well as Admiral Nurses recently being employed locally in Dorset. Kitbag groups were also discussed, however this service is only currently available in Hampshire. Memory Lane groups were mentioned as something that works well for those with lived experience of dementia, however this was not veteran-specific or tailored support for ex-military. Participating veterans and carers suggested that a veteran-specific dementia group would be helpful so that they could mix with others with shared experiences in the military. Signposting and being connected to the “right” people can work really well, however it is often a lengthy process to access the right connections for appropriate support and signposting. This stakeholder event, as well as the workshops run as part of the project, were beneficial both to participating veterans and to attending stakeholders and participants wished for similar initiatives to be started or continued. Dementia groups that are veteran-specific would be beneficial as veterans can often find opportunities for bonding and common interests through their shared time in the military.



## Dream – What might be if no barriers or limits exist?

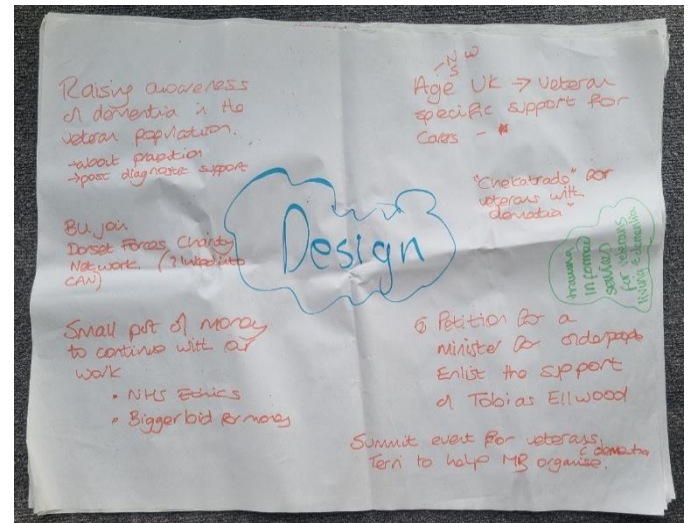
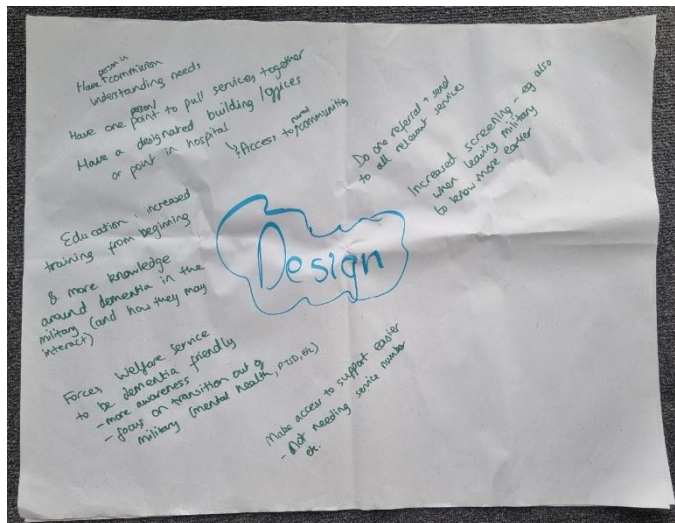
During this session, a key focus across groups was having a central service so that all information, signposting and patient/military records could be kept in one place and veterans having one centralised place to go to for support. From a service provider perspective, this also included services being more joined up and services having more immediate access to records to expedite the help they can give. Solving financial concerns both for veterans and carers day-to-day and support for carers were also discussed. Veteran-specific dreams included access to more personalised care, more admiral nurses being employed by military organisations/charities, fast-tracking veterans' care to reduce their wait times in hospital, no-one going under the radar, and also having no criteria for care needs assessment for veterans. Another dream was for every parish council to have a veteran champion to connect with veterans and signpost to support. A greater evidence base in research for veterans with dementia was also discussed, for example around earlier support, prevention and preparation.

Veterans also stated wanting to have a purpose and being able to still contribute, as well as accessible services to be run by veterans themselves. All dreams are detailed below.



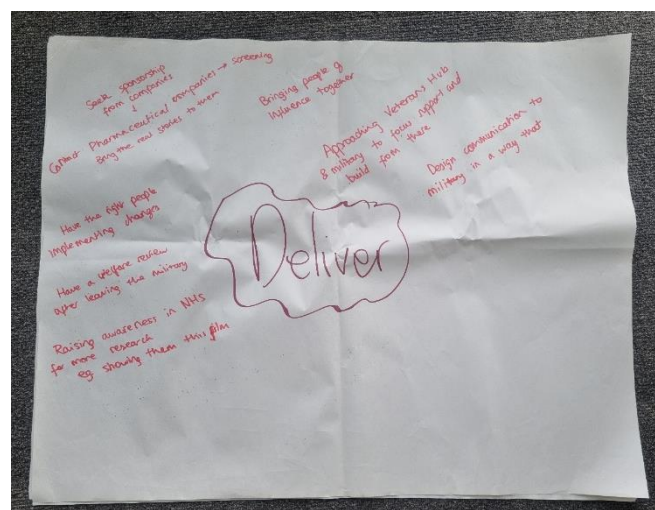
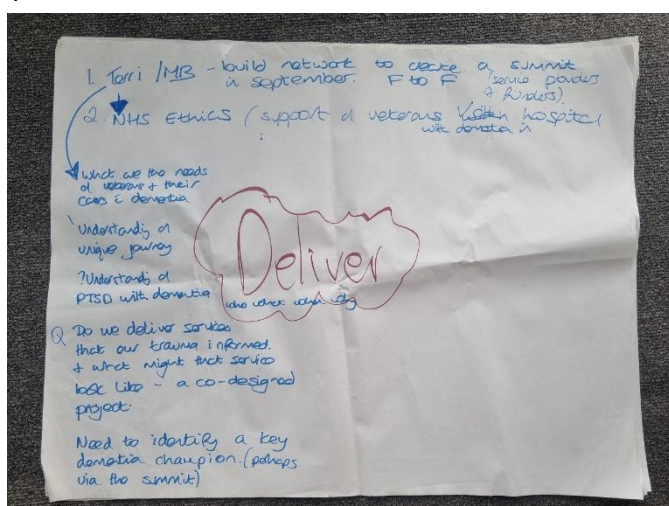
## Design – How could we make this happen?

In the design session, we invited groups to discuss how we might be able to plan for some of these dreams to become a reality. Suggestions included increasing training earlier and having more knowledge around dementia in the military, locating a designated building or office as a point of contact, the Forces Welfare Service becoming dementia friendly and increasing focus on transitioning out of military (for example, increased screening for dementia risk, PTSD, mental health). Also discussed was facilitating access to support by not needing to provide military service numbers, one referral being sent to all relevant services and increasing trauma-informed services for veterans living with dementia. Other suggestions included seeking further funding opportunities for more research on this work, raising awareness of dementia in the veteran population and organising further event(s) for veterans with dementia and stakeholders to continue the conversation.



## Deliver - What plan can we put in place now to make this design happen?

In the final structured session of the day, we invited groups to discuss what plan we could put in place to make this design happen. A key goal in the delivery discussion was formulating a plan to organise a summit event to bring together other stakeholders, designing appropriate communication to military personnel, and raising awareness both within and outside of the NHS by sharing the documentary film from this project. Further comments are shown in the pictures below.



## Conclusion

The stakeholder event day was a successful day bringing together key stakeholders and people with lived experience to harness joint conversations about this important subject. There was an overwhelming willingness to help veterans living with dementia, but also barriers that needed to be addressed to facilitate this. Commonalities were found in both groups' responses, and it was also important to reflect on the different perspectives and ideas brought by each attendee from their individual backgrounds. Noteworthy suggestions were made on the improvement of veteran-specific services and plans were designed to help facilitate this, although wider help would be necessary (both financial and organisational). The pledges section at the end of the day helped each attendee to target a specific helpful action to follow up after the event and focus on veteran-specific help will continue to be explored.

## **Collaborator list**

**Bournemouth University** Associate Professor Michele Board; Rebecca Dew; Kate Jupp; Emma Lucas; Brad Gyori

Benjamin Obojememe - Filmmaker

Vikki Tweedy - Dorset County Hospital

Zena Bobbett - RBL Admiral Nurse

In Jolly Good Company – Workshop Facilitator

The Friendly Food Club – Workshop Facilitator

Rhythm Generation – Workshop Facilitator

## **References**

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Dementia in military and veteran populations: a review of risk factors—traumatic brain injury, post-traumatic stress disorder, deployment, and sleep. *Military Medical Research* 8,

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