

Working together in Dementia Care

Partnership Event

School of Health and Social Care

University of Essex

15th May 2025

Summary: This report is a summary of the partners involved in this event, overview of the presentations, the workshops, discussions and a presentation of the feedback.

Project Team: Prof. Camille Cronin, Dr Rachel Marrow, Victor Ashby, Rebecca Impson, Marie Alexander, Thomas Currid. Email: demfocas@essex.ac.uk

List of Partners

East Suffolk and North Essex NHS Foundation Trust (ESNEFT) Essex Partnership University NHS Foundation Trust (EPUT) Healthwatch Essex Healthwatch Suffolk CVS, Tendering The Health, Wellbeing and Care Hub, University of Essex Institute of Health and Wellbeing University of Essex Carers of People Living with Dementia (PLWD) Older Adult Mental Health, Dementia & Frailty Service, South East Essex, EPUT School of Health and Social Care, University of Essex, School of Computer Science and Electronic Engineering, University of Essex Research & Enterprise Office (Impact), University of Essex #Dementia Research Network, University of Essex DemFoCAS Research Team



List of attendees

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Programme of the Day – 15th May 2025.

Agenda		
0930-0950	Arrival, registration, refreshments & networking	
0950-1000	Facilitator	Welcome & structure of day
1000-1015	Speaker 1	Rachel Marrow DemFoCAS (Dementia – Fundamentals of Care in Acute Settings)
1015-1030	Speaker 2	Smruti Busari IPHW
1030-1045	Speaker 3	Nancy Smith, MSE
1045-1100	Speaker 4	Rebecca Impson – Magic-DemFoCAS
1100-1115	Break	Refreshments
1115-1230	Activity	Discussion on dementia friendly patient info, website, and environments
1230-1300	Break	Lunch and networking
1300-1315	Speaker 5 Victor Ashby DemFoCAS - mapping	
1315-1400	Activity	Interactive discussion & feedback on patient mapping
1400-1415	Break	Refreshments
1415-1525	Activity	Discussion and planning - How do we collaborate further?
1525-1530	525-1530 Close Part 4 - Round-up	

Aim of Event

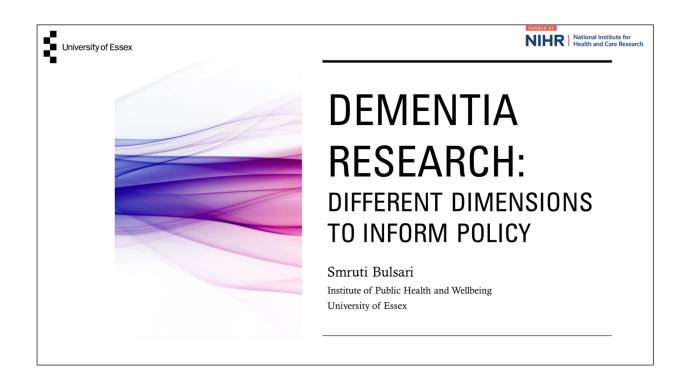
The aim of the event was to provide an update on the project DemFoCAS (Dementia – Fundamentals of Care in Acute Settings), a partnership with East Suffolk and North East Foundation Trust (ESNEFT) and the University of Essex. We also wanted to share related research and activities on and around dementia care in the local area.

Other objectives were to meet and work with our partners, stakeholders, carers and People Living with dementia (PLWD) and share ideas and activities whereby we could present, discuss, and get critical feedback to inform the project. Working with our partners, stakeholders, carers and PLWD is an important part of the DemFoCAS project, and we want to make sure we have opportunities to work together and together with our steering group ensure the project continues to be co-designed, coproduced and co-evaluated.

The event was planned in four sections: presentations, discussing dementia friendly outputs of project, presentation and activity around patient journeys, and finally an activity on collaborative mapping essentially focusing on the next steps.

Presenters Session (Slides presented in the appendices)





South East Essex Ageing Well Carers Intensive Support Team

15th May 2025

Nancy Smith - Carers Intensive Support Lead nancy.smith9@nhs.net





Exploring the use of "Magic Tables" _for people living with dementia _admitted to the acute hospital setting

Proposed PhD Project 2023 - 2026

Rebecca Impson Greenleaf

MSc (Gerontology), BSc HONS (Physiotherapy)

Extended scope Physiotherapist Older People/Frailty at Colchester Hospital & Clinical Academic Research Lead for AHPs at East Suffolk and North Essex NHS Foundation Trust (ESNEFT)

PhD student at University of Essex with the ESNEFT commissioned Dementia - Fundamentals of Care in Acute Settings project (FoCAS) in the School of Health and social care

Presentations



Round Table Discussions

Activity 1

Workshop Exercises - dementia friendly patient info, website, and environments

Camille to introduce activity with 3 areas (use poster or A3) where groups discuss, add to paper and move around adding to the themed discussion

1. Website

Please could you look at the ESNEFT website before the event

Can you find the following:

- Ward visiting times
- How to get to a ward
- Support for a carer
- Support for a PWD If I have dementia what support is there for me?
- Going for a cup tea
- What food are you serving? On the ward? For me as a visitor?
- How do I park my car



Based on this activity discuss ...

- Website being redesigned
- provision of what's available in the community for people living with dementia and their carers
- difficult where to find things, the menus are a bit unclear
- extended visiting hours very unclear and not updated
- Accessible drinking water unclear information about taps that water can be drank from
- link to AccessAble (assessment of access to each ward) is an improvement
- support for people with dementia there is a telephone number, making stays better and support chaplaincy, volunteers, butterfly
- parking good easy to find
- wards individual wards, locations, hours, visiting, phone number, direction, hospital maps
- PALS contact numbers, e-mail, hospital map
- meal times
- virtual tours of community hospitals at lpswich being updated



2. Patient Information

What do patients need?

What do carers need?

In what form should information come in?

Any other ideas

- Options for information (tech), QR codes, written, pictures, video and verbal
- Not to overwhelming
- Communication an information needs to be easy to read and site specific i.e. use yellow paper and use first language
- It should be open and welcoming to manage expectations
- Who to contact up to date details
- Opportunities
- Information and use of "This is me" and how to use it
- Regular contact
- Active involvement and personalised information
- Point of contact on the ward
- Promote patient independence
- Staff to follow instinct on dealing with patients
- Symptoms to be recognised and followed up
- Carers need to understand how the wards work
- Different staff members which is unclear uniforms/lanyards need to be clearer and more understood
- Information point on the ward
- Information pack if discharged to the virtual ward
- Discharge letter to be provided on discharge and not later on
- Carers' pack to be provided
- Easy access to specialist services
- Follow up phone calls
- Patient/carers survey forms
- Provision of crisis line ... to call if in need

3. Environment(s)

How do you feeling when walking in a hospital?

Seems so big in the hospitals

- feeling hopeful to be able to help
- feeling small and not understanding
- feeling lost
- feeling grateful for the supporters
- Feels trust broken but can rebuild (had a different experience after the first bad experience)





- not being familiar with the environment and what to expect
- feeling overwhelmed and concerned about being late
- feels anxious about doing her best
- **Directions** sometimes not very clear, need more visuals
- not being able to understand what the PLWD is thinking or feeling

PLWD are usually admitted via the ED – what can be improved?

- Listen to care of concerns
- listen to family/carers as they can advise the sudden changes and symptoms
- better training for Triage staff
- Better staff understanding about dementia
- less information provided to carer/family waiting
- extra training offered to ED staff re: dementia
- extra staff to support on ED
- Staff to be aware of different types of delirium
- indication how long people have to wait
- consider the environment possible alternative environment
- is signage designed with input from patients and family living with dementia
- Make ED dementia friendly EG bus stop wall paintings reduce noise separate room where possible
- CVST/ Dementia Nurse

Patients (PLWD) often have many ward moves - can we do anything about this?

- Ward moves patient is at risk assess for suitability
- ward environment upgrades some upgrades are old and do not meet needs
- use of tech in areas with no windows
- follow lines to follow

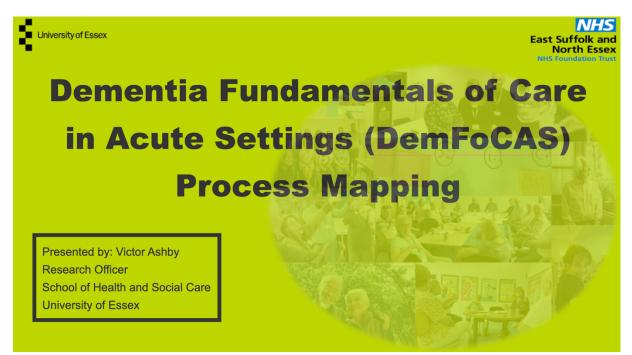
Anything else to add?

- GoPro video of different wards department upload to website to provide reassurance
- wall murals of local landmarks
- Ensuring safety on wards for PLWD
- Personal items/glasses/teeth/hearing aid
- Explore opportunity to have young volunteers in ESNEFT



Speaker 5 and Activity 2 (Victor)

Presentation and introduce a table focused activity to each group



Interactive discussion and feedback on patient mapping

1.	How can we reflect the	Ensure it is provided and completed. It should be taken with patient on their
	usage of 'This is me' in	care journey
	care notes?	Epic will store this information
		Will be linked to my NHS record
		It should be used
2.	What does a 'usual place	Own home, where someone lives
	of residence' mean to	Causes problems with telephone communications
	you?	It is important to get this right for discharge planning
		Notes need to be updated/addressed and communication of
		admission/death system doesn't link
		May get better with NOVA
3.	What are the	Bed moves are used to meet need. Ward moves are done to meet specific
	differences/similarities	medical needs
	between a patient bed	The reason for admission may be the priority and there may not be a bed
	move and a ward move?	available
		The move can be related to the primary condition
		Probably used interchangeably: Bed move – patient is moved nearer for
		observations if deteriorating in the ward; Ward move – move from one ward
		to another based on bed pressure or speciality
		PWD should not be moved/should be avoided

4.	Are patient care notes	Should be checked	
	checked at discharge?	Notes should be summarised for discharge summary	
		Notes do not usually reflect the patient's status	
		How do we know the notes are being checked	
5.	How does EPR change the	Store all information in one place	
	way we collect case	Improve accuracy in the Trust for notes	
	notes?	Epic is the leading global pt record	
		Epic has taken over "Marie's life"	
		Red flags and issues will be time stamped – no more written notes	
		The interface will be used for primary care for ESNEFT only	

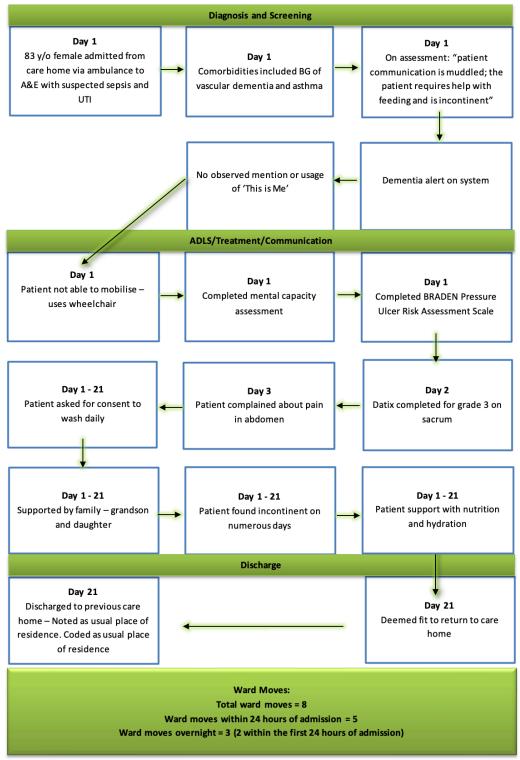
Scenario for question 6

Jill, aged 82 is a lady living with dementia, her husband Jack aged 83 is the primary carer. Jill has a fall and is admitted to the 'Fundamentals of Care Hospital' with a minor head injury. Upon admission, Jill expresses with aggression and violent behaviours, these behaviours continue whilst Jill is in hospital. On day 3 when Jill's head injury is no longer apparent, the consultant prepares for discharge at Jack's request. Jack shares that Jill does not usually behave with aggression and violence when staying at their private dwelling. The MDT team persuades Jack who stayed the entire day with Jill in hospital to go home and rest. On the morning of day 4 the MDT team discusses safeguarding issues for the husband Jack, they agree that Jill needs more appropriate care. Jack is then told that afternoon that Jill needs to complete some tests to ensure that she is fit for discharge. Over the next few days Jill is medicated and cared for. She is eventually discharged to a temporary place of residence.

		Include Jack in the process. Were Jill and Jack consulted. Is this behaviour	
6.	Was this the best outcome	temporary?	
	for Jill and Jack?	All agreed no	
		Did they ask Jill?	
		Sent Jack home while making decision	
		Did they include Jack in the prep for home	
		Assumption vs safeguarding – did they listen to Jack?	
		Need a more PCC approach – more communication was needed	
		Capacity + best interest for patient	
		Preferences were not considered	
		Could Jill go home?	
		What community services were involved?	
		Was the aggressive behaviour temporary?	
		Can we influence patient behaviour in hospital?	
		Need to review the behaviour charts	
		Include Jack in the process	

Conventional Process Mapping

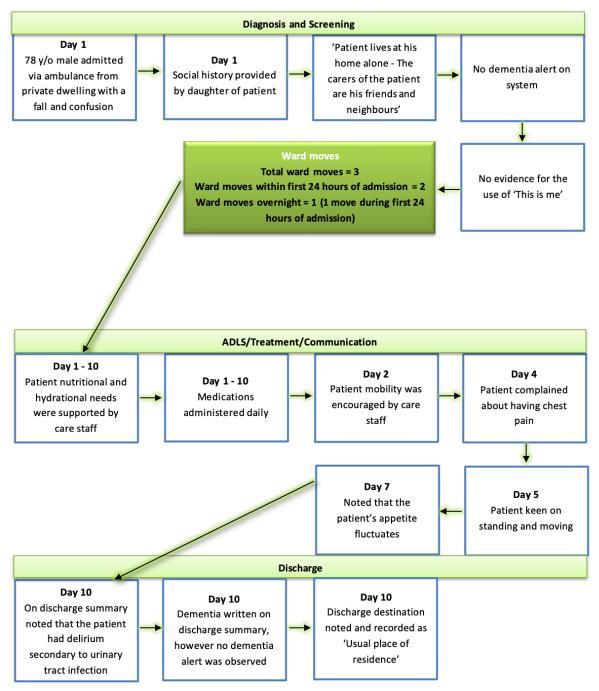
Case 4 – what does muddled mean? Suspected sepsis and UTI but the reader is unaware of the outcome of these presentations Day 3 "pain in abdomen" needs further investigation Too many ward moves within the first 24 hours





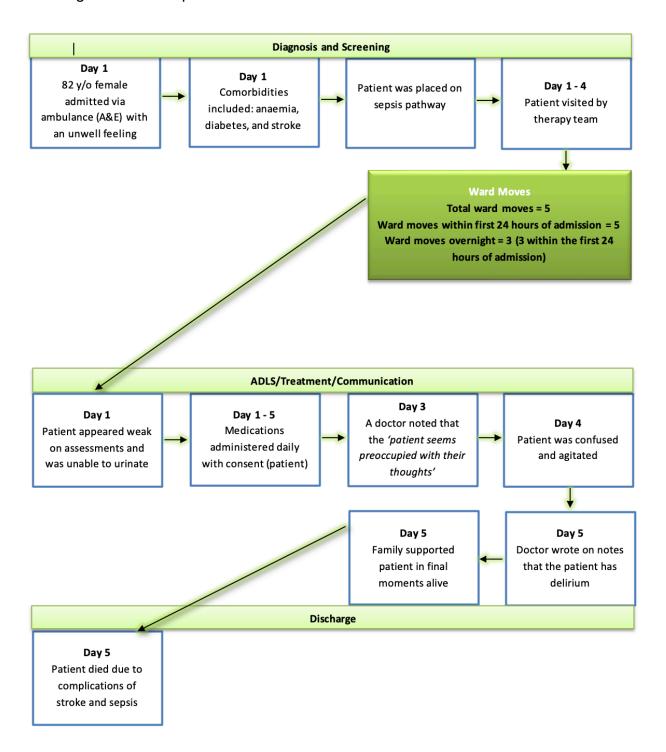
Case 5

"This is me" - should be a digital passport Need to know what support was needed for the patient during their stay Where did the dementia diagnosis come from?



Case 6

Too much time taken trying to figure out the problem Ward moves may have been necessary Not enough information provided



Activity 3 - Collaboration Roadmap

How do we collaborate further?

Purpose:

To help mixed stakeholder groups (researchers, clinicians, academics, service users) reflect on what's next, identify shared goals, & outline steps for future collaboration.

Group Work: Collaboration Roadmap (30 minutes)

Each group fills in the roadmap collaboratively, answering and discussing the following:

1. Shared Vision (5 mins):

What do we want to achieve together in the next 1–2 years? (Focus on shared values and outcomes) Evidence DemFoCAS has contributed to change Review care records and changes after EPIC Holistic approach to health Review service by ECC as wrong contract strategy Health model GP accessible/confident referral to Kingswood Increase support for Ness and Holly for adequate support on wards Dementia services to have bigger teams and more oversight Delirium as a separate group High volume of patience in ESNEFT cohort versus number of staff Supporting patients in the right place and admissions avoidance, appropriate diagnosis invest in services i.e. CIS signposting

2. Challenges & Barriers (5 mins):

What could get in the way of collaboration? How might we address it? Changes in personnel Organisational changes Government decisions There are no robust Essex dementia strategies in place Dementia being de-prioritised Funding Linking community in to NHS Reorganising & funding to reopen Colchester helpline Set patient expectations with GP and hospital in advance Money, time, awareness of service, staffing levels, resources and demographics

3. Opportunities & Strengths (5 mins):

What assets or opportunities do we bring individually and collectively? Diverse experience We are a collective voice with similar values and beliefs Using good practise from other areas to influence ESNEFT is an area of opportunity People present today ECC contracts for carers support They have a competitive collaborative model



Carers voice at Healthwatch Basics EG pain and Constipation how do we get this right and support patients to communicate

4. Who Does What (5 mins):

Who is interested in being involved, and what roles might they take? Volunteer roles for Magic tables (CS) Ambassador role (NS) View on procurement strategy ECC Health and Wellbeing at the University Ness already involved

5. Next Steps (10 mins):

What are 1–2 concrete next steps or pilot ideas we can explore together? Keep in touch (how?) Email list, LinkedIn, zoom calls/meetings, t Task and finish group Involve ECC Carers Voice needed at hospital, More volunteers in the community hospitals and volunteering initiatives

Part 4 - Round-up

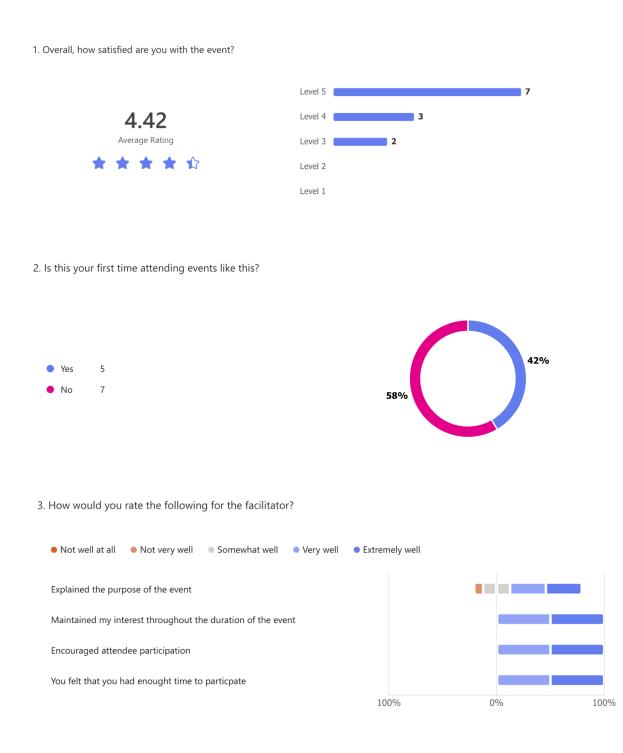
Bring everyone together, thank and advise how feedback will be given

- We will collate evaluations, draw up a summary report and circulate presentations.
- We will follow up with an online meeting.

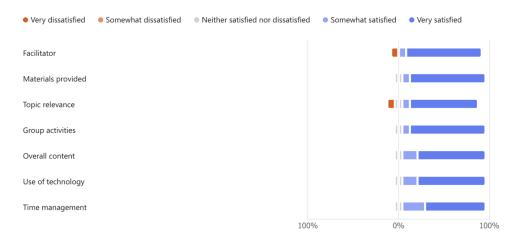
Evaluation

After the Working Together in Dementia Care Event, a QR Code was shared with the audience to gather an evaluation of the event, and a further email together with circulating the presentation slides.

Summary of the evaluation – feedback from 12 attendees.



4. How satisfied are you with the following aspects of the event?



5. How likely are you to recommend the event to a friend or colleague?

			0	
Promoters	9			
Passives	1		58	
Detractors	2	-100	50	+100
			NPS®	

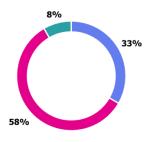
6. Were your expectations of the event met?

4

7

1

- Beyond my expectations
- Met as expected
- Below my expectations



7. How could the event be improved?

5 Responses

$ID \uparrow$	Name	Responses
1	anonymous	A proper lunch
2	anonymous	Let's have more meetings like this
3	anonymous	Cant think of any improvements at this time
4	anonymous	Perhaps having discussion forums designed to answer specific questions. This could help engage the audience more and give them more room to share.
5	anonymous	Action Plan

<u>1</u>

Summary

The "Working Together in Dementia Care" event, held on 15 May 2025 at the University of Essex, brought together researchers, clinicians, carers, and people living with dementia to share progress on the DemFoCAS project and explore wider dementia-related research and care initiatives. The programme included presentations, interactive workshops, and in-depth group discussions around patient information, hospital environments, and collaborative care mapping. Feedback from participants highlighted the importance of accessible information, personalised care, better communication, and continued multi-agency collaboration. The event fostered a strong sense of shared commitment and created a space for generating practical ideas to enhance dementia care across hospital and community settings.

Conclusion

This event underscored the value of partnership, co-production, and shared learning in addressing the complex needs of people living with dementia. Participants identified several systemic challenges—such as fragmented services, unclear care pathways, and under-resourced environments—but also recognised significant opportunities to drive meaningful change through collaboration. The DemFoCAS project continues to provide a vital platform for innovation and feedback-led improvement in acute care for people with dementia. Maintaining this momentum will require sustained engagement, cross-sectoral leadership, and inclusive planning that prioritises the voices of carers and those with lived experience.

Recommendations

- Improve Accessibility of Information
 Ensure dementia-friendly design of hospital websites and physical environments; provide clear, simple, multi-format information for carers and patients.
- Strengthen Communication at All Stages of Care
 Prioritise clear roles, consistent staff identification, and proactive updates throughout a
 patient's journey—especially during transitions like ward moves or discharge.
- Promote the Use of Tools Like "This is Me" Standardise use of patient-centred documentation to personalise care and improve continuity across settings.
- 4. Enhance Dementia-Specific Staff Training Increased awareness and specialist training in frontline services, including emergency departments, to better respond to dementia-related behaviours and needs.
- 5. Foster Collaborative Research and Practice Continue engaging stakeholders in co-design and co-evaluation of services; build on the strengths and experiences within the network.
- Increase Visibility and Engagement of Carers
 Include carers more actively in decision-making and provide accessible, tailored resources to
 support their role.
- 7. Leverage Technology Thoughtfully Explore digital tools like QR codes, virtual tours, and patient portals to support information sharing and engagement.

Next Steps

• Collate and share this summary report and presentation materials with attendees and partners.

- Establish a regular follow-up forum (email group, Zoom check-ins, or LinkedIn group) to maintain communication.
- Form a "Task and Finish group" to explore key pilot ideas, such as a volunteer support initiative or the digitalisation of the "This is Me" passport.
- Engage local authorities and community providers, including Essex County Council and Healthwatch, in strategic planning discussions.
- Plan a future Dementia Network conference, involving people with lived experience, to review progress and deepen collaboration.
- Monitor and evaluate the implementation of these recommendations through regular stakeholder input.

Acknowledgments

Thank you to Event Essex

Thank you

A big thank you to all that attended.