



Gwynedd Local Authority: Dementia Actif Evaluation



"I can guarantee you, once people have been to a Dementia Actif session, they will come back".

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Bangor University, September 2023



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Abstract

Background

The overall aim of this study was to evaluate the Dementia Actif programme delivered in one local authority area in North Wales. Dementia Actif provides group physical activity opportunities to support and enhance the quality of life for people living with dementia (PLWD) and their carers. The activities offered include physical exercise classes, Boccia league, online activities and various clubs e.g., gardening.

Methods

This evaluation of Dementia Actif focused on four key workstreams (WS). Data collection took place between January and June 2023.

WS1: *Rapid Literature Review.* The search included articles and grey literature published between 2012 and 2022 (a 10-year period). All study designs were included, with keywords limited to the English Language. The following bibliographical databases were searched: CINAHL (EBSCO), PsycInfo, ProQuest, Web of Science, to identify 18 relevant global journal articles.

WS2: *Interviews and focus groups with professional stakeholders* (n=14) from Health, Social Care and Third Sector services who refer PLWD to Dementia Actif, within one local authority area in North Wales.

WS3: *Observation of activities* completed by the researcher, including exercise classes and wellbeing activities within leisure centres across the local authority area.

WS4: Interviews with PLWD and their carers (n=6) who access Dementia Actif, including analysing specific case studies.

Findings

The findings from the rapid literature review reflect a lack of global evidence of approaches focused on measuring social interaction, wellbeing and building on community assets to address the needs of PLWD and their unpaid carers. Results from WS2-WS4 indicate the positive impact of an active/wellbeing model for supporting PLWD and their carers, in particular the use of preventative community-based resources to support unpaid carers and reduce the need for admission to acute secondary and residential care.

Interpretation

The analysis indicates the benefits of low-cost social activities on overall wellbeing outcomes, including giving PLWD and their carers voice, choice and control over their own wellbeing outcomes to connect them with their community. This evaluation argues the potential to use Dementia Actif approaches to address complex needs. However, this was based on a small sample, which may impact on the broader applicability of the findings.

Gwynedd Local Authority: **Dementia Actif** Evaluation

1. Introduction

Gwynedd Council requested an evaluation focused on exploring the Dementia Actif service in the context of the Social Services and Well-being Act (Wales) 2014 and the Dementia Wales Strategy (2018-2022) and also the North Wales Dementia Strategy (2021).

Gwynedd Council's Cabinet asked for a formal evaluation of the Dementia Actif Service in order to consider long-term funding options. The overall aim of this evaluation was to review and evaluate the Dementia Actif Service delivered in Gwynedd. The intention was to explore these key points:

1.1 Process

- What is the vision of Dementia Actif, how does it connect with the vision for older people?
- Is Dementia Actif fulfilling its purpose? e.g. suitable users, number of users, number of sessions, costs
- Is it doing this well? e.g. timely intervention, suitable staffing, convenience of location of sessions, frequency of sessions

1.2 Outcomes

a) Impact on people

- Do the individuals' circumstances change? e.g. ability, knowledge, attitude, understanding, keeping fit, resilience
- To what extent has Dementia Actif caused this change?

b) How does the Team measure impact?

- Are the life outcomes of the individuals who have been a part of the scheme different to those individuals who weren't a part of the scheme?
- How were things before the existence of Dementia Actif?
- Have we been using a method of measuring impact, e.g. the results 'star'?
- Are there any related measures that will help with measuring, e.g. individuals being supported from home for longer, financial savings.
- The opinion of the users, their families and friends has the service made a difference to them, in what way, use stories.
- The opinion of other professional officers who are working with the individuals.

The objectives were focused on identifying and exploring the uses and limitations of the current Dementia Actif Service. To feedback the results of the evaluation to the Gwynedd Council's Adults, Health and Well-being Management Team. To offer analysis and key recommendation to advance knowledge to inform the development of the Dementia Actif Service.

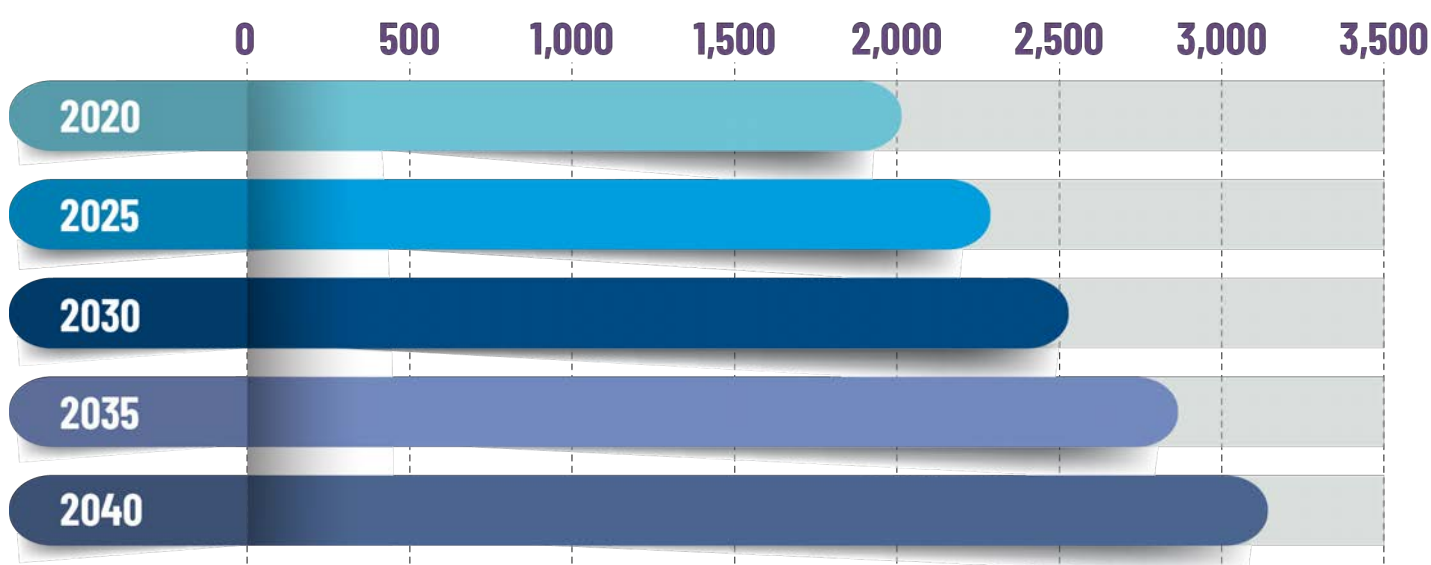
2. Background and Context

2.1 Understanding Dementia

2.1.1 The nature of the problem

Dementia is a progressive syndrome that affects deterioration in cognitive function. Dementia is a growing issue, with significant social and economic costs across global communities (Alzheimer's Disease International, 2016; World Health Organization, 2021). The World Alzheimer Report (Alzheimer's Disease International, 2016) outlines key recommendations to strengthen healthcare systems, including a focus on reducing the over-specialisation of dementia care, improving access to training and mentoring and reducing the gap between policy and research. Global evidence reflects that over 55 million people are living with dementia (PLWD), with a projected 10 million increase to this figure each year (World Health Organization, 2021). There are more than 920,000 people in the UK living with dementia, a figure expected to rise to over one million by 2021 (Alzheimer's Society, 2019). It is estimated that there will be at least 100,000 people living with dementia in Wales by 2050 (Alzheimer's Society Cymru, 2021).

Graph 1 illustrates the projected increase in the number of people over 65 years old in Gwynedd with dementia, with an estimated increase of PLWD of 53% over a twenty-year period (North Wales Population Needs Assessment 2022-2027). However, due to the nature of the illness, low diagnosis rate and the stigma associated with dementia, this projected figure will be higher.



The total cost of dementia in the UK has been estimated as £26.3 billion, with £4.3 billion attributed to health care costs, £10.3 billion to social care and £11.6 billion for the costs of unpaid care (The Alzheimer's Society, 2013).

PLWD are more likely to be hospitalised due to their perceived needs and risks (Cunningham and Archibald, 2006) and are more likely to remain in hospital for longer (King et al., 2006). The Francis Inquiry into the Mid Staffordshire NHS Foundation Trust (The Mid Staffordshire NHS Foundation Trust Public Inquiry, 2013) revealed that PLWD were specifically vulnerable to poor standards of care. This was further exacerbated for PLWD with no family to advocate on their behalf.

Person Centred Care (PCC) is defined as an approach focused on developing a value base that understands the bespoke needs of each person with dementia, with a focus on gathering a sense of their worldview in order to support their holistic needs (Kitwood, 1997). Evidence reflects that PCC can benefit overall well-being outcomes, in particular around understanding and addressing the needs of PLWD, including attachment, comfort, inclusion, occupation, and identity. The principles of PCC should underpin good practice when supporting PLWD, focused on a personalised and relationship-based approach promoting positive well-being. Whilst it is acknowledged that PCC is the best practice approach, there is a significant gap between understanding and applying this model into practice.

2.1.2 The Social Policy context

Welsh social policy is focused on a right-based approach to supporting PLWD and their families. The Welsh Government launched a four-year dementia action plan (2018-2022) (Welsh Government, 2018), with each local authority area developing a local dementia plan, with a focus on developing Wales to be a dementia friendly nation. For example, the North Wales Dementia Strategy (2020, pages 4-7) noted several key areas of access to services in the community, including:

- An increased awareness about dementia, particularly because of 'dementia friendly community' schemes.
- Joint working between specific teams and with different organisations.
- Assessment and diagnosis.
- Specialist nurses to support people with young onset dementia and people with learning disabilities who have onset of dementia.
- Beginning to develop early detection screening for dementia with individuals with learning disabilities and Down's syndrome.



With key areas that require further development and improvement:

- Support for carers.
- Risk reduction and delaying onset.
- Raising awareness and understanding.
- Recognition and identification.
- Assessment and diagnosis.
- Living as well and as long as possible with dementia.
- Need for increased support.

2.2 Developing Dementia Actif

2.2.1 Service Background

Dementia Actif Gwynedd was established initially under the name of 'Dementia Go' with funding from the Integrated Care Fund (ICF) in 2014 when the project was within the National Exercise Referral Scheme (NERS). It developed into a specific Team within the Leisure Department of Gwynedd Council before transferring to the Adults, Health and Well-being Department during June 2018 and became a part of the Well-being Service. The Team was originally funded under the ICF but is now funded by Gwynedd County Council.

Detailed information has been provided around the progress and development of the Dementia Actif Service (see Appendix 1: Service structure). This information provides a picture of a Service that has developed and been driven by three key factors:

- the enthusiasm and commitment of all the Dementia Actif team members.
- the interest, demand, and commitment of Gwynedd citizens to attend the Dementia Actif activities.
- the willingness of the local authority to support the development of this innovative service.

The original aims of the Service in 2014 were focused on three key areas:

1. **Reducing the risk of dementia:** To increase awareness of modifiable health related risk factors which can help reduce the risk of dementia – 40yrs+
2. **Living well with dementia:** To support people with dementia, relatives and carers to live well with the condition.
3. **Dementia friendly communities:** To raise awareness and educate communities about dementia and to create opportunities.



Following the formation of the Dementia Actif Service, the intention was to measure the outcomes of these three aims by adopting a variety of methods, including quality of life questionnaires, case studies, video interviews, functional exercise test (sit to stand) and the creation of dementia friendly communities within the leisure centre environment across Gwynedd. On average 75% of those who were assessed through the improvements in the Quality-of-Life Questionnaire and physical assessments evidenced that the Dementia Actif exercise activities assisted in maintaining positive daily living and improved the quality of life (True Value Report, 2019).

Previously known as DementiaGo, the service launched a new name as part of the re-branding in January 2021 to demonstrate the service developments and offer that goes beyond the provision of exercise classes. To coincide with this re-branding, a website was launched and funded by donations (<https://www.dementiaactifgwynedd.cymru/en/>). The Service has generally developed in a fluid manner, with recent evidence demonstrating emerging links to strategic planning and development to inform the Service growth. The services offered have also adapted to changing needs and circumstances, illustrating a commitment to person centred care and the willingness and ability to be adaptable. For example, during the COVID-19 global pandemic the emphasis and aims of the project were adapted to respond to the crisis. Due to the prohibition of face-to-face contact, the emphasis during this time was for the service to be proactive in keeping connected to support people living with dementia (PLWD) and their cares in a person-centred manner. The evidence demonstrates that the Dementia Actif team were both creative and proactive in how they met a broad spectrum of needs.

2.2.2 Menu of activities and interventions

The menu of activities has continued to evolve and develop to offer a broad range of online and face-to-face options. These have included gentle exercise classes, sporting memories classes, Dawns i Bawb, coffee mornings, dementia carers support group, Tai Chi movement for wellbeing, delivering the Alzheimer's Society Dementia Friends Information sessions.

2.2.3 Data Evidence

The overview data from 2019 until 2019 illustrates the significant increase in the demand for the service during this 5-year period. Graph 1 outlines the increase in participation in classes and other events (True Value Report, 2019).



Attendances

Classes and other events



During 2019-2020, the data in Table 2 highlights the attendance at Dementia classes:

Activities	Engagement
Exercise activities	Average weekly attendance: 80
Attendance at all other activities	1,130
Number of new dementia friends	190
Attendance at dementia bus tour	144
Number of teams in the Boccia league	18



During the COVID-19 global pandemic of 2020-2021, Table 2 reflects the change in services, with the service adapting to offer a higher level of online activities and support:

Methods of staying connected	Engagement
Members on register	173
Members who are digitally connected	58%
Members Not digitally connected	42%
Phone calls/text messages/WhatsApp	3,000
Pen Pals Scheme (intergenerational)	9
Members supported with digital devices	5
Newsletter 108 sent by post 98 by email	18 additions. 206 copies per month. 3708 copies per year.

During 2022-2023, the aim was focused on delivering effective sessions online and face-to-face to support PLWD and unpaid carers, developing and strengthening partnerships post COVID-19 and developing new opportunities. The data in Table 3 reflects the level of participation and the increase in participation face-to-face activities as the year progressed.

Total Attendances		Online	Classes and Activities	TOTALS
Quarter 1	Apr-Jun	169	1248	1417
Quarter 2	Jul-Sep	183	1083	1266
Quarter 3	Oct-Dec	298	1331	1629
Quarter 4	Jan-Mar	129	2109	2238
TOTALS		779	5771	6550

During 2022-2023 new data was gathered around income generating and the level of visits to the Dementia Actif website, with the data in Table 4 reflecting:

Table 4: 2022-2023 data: Income and website visits

Number of Website visits	84,135
Income from Community Classes	£5,544
Income from Donations	£5,105

The total income generated amounts to £10,649. This demonstrates the ability of the service to generate income and the potential to generate further income through robust business planning. Also, recent data illustrates the growing demand for the service, with a total of 129 new referrals for this period.

There has also been significant success in disseminating the learning and growth of the service through local and national media platforms, for example, a segment on BBC Countryfile in 2018, which was viewed by 10 million.

2.2.4 Developments

As mentioned, a key driver for all the service developments is the enthusiasm and commitment of the team members. On observing the team together, there is clear presentation of a connected and cohesive team. There is also commitment to the wellbeing of the staff members, who stay connected through regular team meetings, the WhatsApp group and various team activities e.g. walking meetings, mindfulness sessions etc. The team also network across multi-agency services and with policy and research, for example, the connection with the Centre for Aging and Dementia at Bangor University.

The original Intermediate Care Fund (ICF) funding bid for the service in 2015/16 clearly illustrates the service origins with limited resource and a total of 54 hours weekly staffing support. The provision offered in 2023 has exceeded the expectations of this original ICF funding bid, with continued innovation and yearly growth. The detailed and ambitious plan, the YouTube marketing video and the focus on 'real world' case studies, clearly demonstrates the commitment and vision for this service from the outset. These developments have continued, for example, the new dementia tour bus planned for October 2023 is oversubscribed, illustrating the continued demand for awareness raising and activities. In partnership and consultation with frontline services, new activities and classes have been scheduled for September 2023 in Bala and Penygroes. The aim of the newly formed Dementia Gwynedd Super Group is to meet on a three monthly basis to share Development that can further inform the progression of the Dementia Actif Service. The development and commitment of the team has not gone unnoticed, with invites to regularly present on their work at UK based conferences, including the Lancet Public Health conference in November 2023. The innovative work has also been recognised, for example, being a finalist at the Social Care Accolades awards in 2020. The Dementia Actif lead has regularly shared developments, regular progress reports and rich case examples across several multi-agency partnerships. (see Appendix 5 for example of case studies).



3. The Evaluation Process

In terms of the methodology and the small-scale nature of this commission, the following methodology was proposed and agreed with Gwynedd Local Authority as the commissioner of this evaluation.

Step 1: Analysis of secondary data: To measure the vision, measure some outputs (e.g., timely intervention) and review.

Step 2: One-to-one semi-structured interviews with relevant professionals on a multi-agency basis to gather insights into their attitudes and experiences of Dementia Actif. All interviews were offered over a virtual platform (e.g., Microsoft Teams) or via telephone.

Step 3: One-to-one semi-structured interviews with people living with dementia who have used the service to gain an idea of the attitudes and experience. All interviews were offered over a virtual platform (e.g., Microsoft Teams) or via telephone (whatever best suits the needs of each participant).

Permission and consent were also granted to use the case studies gathered as part of the performance data of Dementia Actif.

3.1 Sampling & Recruitment

The lead for Dementia Actif and the Well-being Manager assisted the researcher to identify potential study participants. The Dementia Actif Team have links with both sample groups (professionals and individuals accessing services). The contact details of all key professionals/stakeholders were provided to the researcher (following receipt of their consent to share this information). A bilingual study information pack was shared via email with all potential participants, including a participant information sheet, a consent information sheet, and GDPR sheet. The contact details of the researcher were included as part of this information pack, with the invitation for any potential participant to contact the researcher to discuss participation and to ask any questions.

The intention was to co-produce the development of the evaluation with key stakeholders. This included pre-project engagement with key stakeholders to co-produce both interview topic guides. A broad range of stakeholders engaged in the evaluation, including key partners from Adult Social Care, Betsi Cadwaladr University Health Board, Alzheimer's UK, Byw yn Iach, Public Health Wales, external providers and Gwynedd Councillors.

3.2 Data management and Analysis

Interviews were audio-recorded, transcribed, and checked for accuracy. The researcher used a GDPR compliant transcription service. Following the research interview, thematic analysis of the transcripts was completed (Braun and Clarke, 2006).

3.3 Ethical considerations

Electronic data was stored on the university drive with the researcher discussing the confidential and secure storing of electronic data with the IT department prior to the commencement of fieldwork. Therefore, anonymised interview transcripts were stored on the secure university server in accordance with the Data Protection Act 2018.

In advance of the interview, each participant was briefed by the researcher on the project information sheet and the consent form. If any potential participant living with dementia could not give informed consent (due to impaired capacity), then the researcher discussed with the gatekeeper (and the social worker, if suitable) around the suitability of requesting proxy consent from a family member. Consent was ongoing and a flexible process (e.g. consent was revisited again at the start of the interview).

An ethical issue with dementia research is that people without supportive family or carers may be excluded from the research (and its benefits) because they lack adequate representation. Therefore, where an individual could not consent and does not have a suitable family member to consent on their behalf, consideration was given to discussing further with the social worker and the multi-disciplinary team (if suitable). The aim was to include rather than exclude potential participants in a respectful and dignified manner (as they wish). Therefore, supportive decision making was undertaken to ensure ethical safeguards. As per the MCA 2005, mental capacity was assumed unless proved otherwise. The researcher took full consideration of the DEEP-Ethics Gold Standards for Dementia Research (DEEP, 2020) throughout the research process.

It was agreed in advance with the gatekeeper that confidentiality would be breached on a 'need to know' basis if an adult protection concern or risk of significant harm arose. Full consideration was given to any legal requirement as per Part 7 of the Social Services and Well-being Act [Wales] 2014. If adult protection concerns arose, consideration was given to whether immediate action was proportional or whether direct discussion with the Lead Manager was required. Essentially, absolute anonymity or confidentiality could not be guaranteed due to safeguarding requirements, which was clearly explained to participants. To adhere to good practice and create 'defensible' processes, a simple protocol to address any potential safeguarding concern was drafted in partnership with Wellbeing Manager at Gwynedd Council as the 'gatekeeper' for this evaluation. No safeguarding concerns arose during this evaluation.

Careful consideration was given throughout to the suitability of conducting focus groups and interviews via a virtual platform (Teams/Zoom). All interviews were completed over TEAMS and started with a review of the Information Sheet and the consent form. Assurance was given that the Interviewer was within a confidential and secure room that could not be accessed by anyone else (to disturb or listen to the interview). The interviewer also used headphones to protect confidentiality.



All project information was available in the participant language of choice, with all project information available in Welsh and English, to ensure that 'Active Offer' of language choice throughout. Consideration was also given to other communication needs (e.g. easy read, Talking Mats).

Participants were advised that they may skip questions or terminate the interview anytime. If participants become distressed during the focus group or interview, they would have been asked if they feel able to continue, wish to have a break or wish to withdraw from the study. There were no signs of distress identified during the course of this evaluation. Participants were informed of their right to withdraw from the research at any point before or during the interview, including up to 6 weeks post interview. There was no expression of a wish to withdraw from the study. Each participant interview was coded and tracked to ensure that the data could be easily identified and removed if required. Post interview advice/pathways of support was included as part of the participation information sheet. The Well-being Manager agreed to be the lead support if any participant requires additional support following the completion of the interview.

No incentives, vouchers or rewards were offered as a form of enticement to participate as per good practice as 'incentives' may be coercive, persuasive or impose certain level of pressure to participate (Alderson and Morrow, 2011). This was agreed with the Gwynedd County Council.



4. Rapid Literature Review

This section briefly introduces the literature review search process, followed by a summary of the findings outlining the relevance to the development of the Dementia Actif Service in Gwynedd.

4.1 Summary of Rapid Literature Review process

A rapid literature review was undertaken, with the question, aim and objectives guiding the research process. To inform the literature search, the principles of a rapid literature review were followed. For the purposes of this evaluation, a rapid literature review is defined as a process that uses modified systematic review methods to expediate the review process while maintaining systematic, transparent and replicable methods (Klerings et al, 2023). The focus was to undertake the literature review to determine the key themes, findings and gaps in the available global literature.

The following bibliographic databases were used as key search sources: CINAHL (EBSCO), PsycInfo, ProQuest, PubMed and Web of Science. The key search terms outlined in Table 5 were used to inform the search process.

Table 5: Key search terms

Search topic/question	The overall aim of this evaluation is to review and evaluate the Dementia Actif Service delivered in Gwynedd.
Initial keywords	"Dementia" AND "activit*"
Additional keyword	"people living with dementia" OR "Alzheimer's" AND "interventions" OR "exercise"

To ensure the relevance to current practice, the search period spanned a 10-year period from 2012 to 2022, with all study designs included, with keywords limited to the English Language. In addition, a 'snowball' approach was used to identify the relevant literature, as simply completing an electronic search can never be fully comprehensive. Whereas using multiple electronic bibliographic databases was the main component of the search strategy, it was not the only component as multiple strategies enhance the thoroughness of the search (Aveyard, 2014). In order to manage publication bias, the literature search also included grey literature, specifically unpublished literature, such as government documents that met the inclusion criteria, as recommended by Berkeljon and Baldwin (2009). Papers were excluded based the inclusion and exclusion criteria outlined in Table 6. The literature sample screening process firstly focus on title screening for relevance, followed by abstract review of potentially relevant papers and finally the full paper review of remaining articles.

Table 6: Inclusion / exclusion criteria

Criteria	Inclusion	Exclusion
Setting	Dementia activities in community settings Research focused on adults aged 65+ years	Activities based in inpatient/ outpatient settings within a hospital, including hospital day centres and rehabilitation wards. Community based support focused on home-care and community day opportunity support. Research focused on adult below the age of 65 years old
Aims	Research focused on the provision and quality of care and support.	Studies that explored clinical aspects of dementia (e.g. prevalence, assessment, diagnosis) were excluded.
Design	Any study design	None excluded
Language	English or Welsh language	Any other language
Peer review	Peer reviewed and grey literature included.	News articles, blogs, conference abstracts, MA dissertations'
Dates	2012-2022: limiting the scope to the past 10 years.	Studies prior to 2012

Following the screening process, the final literature sample included n=18. The sample papers were reviewed and analysed to inform the findings summarised in the next section.

4.2 Workstream 1: Summary of Findings from Rapid Literature Review

4.2.1 Overview

On a global scale, dementia is one of the major causes of disability, which has a significant impact on health and social care services, the long-term and increasing economic costs (World Health Organization, 2023). The effect of dementia on PLWD and unpaid carers is multi-faceted and impacts on behaviour, physical and emotional wellbeing. This in turn influences lifestyle and general everyday activities. Due to the complex nature of this problem and the global increased prevalence of dementia, it is crucial that we understand the protective factors that can support PLWD and unpaid carers.

Although pharmacological treatments may slow decline in cognitive and functional abilities, there are no disease-modifying drugs available for dementia (Groot et al., 2016). Due to age-related bodily and health changes, older adults are at high risk for adverse side-effects from such medications, especially when prescribed a combination of medication (Buckley and Salpeter, 2015). Therefore, evidence-based, safe, and effective nonpharmacological treatments are required for PLWD to maintain and improved wellbeing as it is difficult to manage symptoms of dementia only with medication.

The benefits of an active lifestyle are well-known, including the positive impact on physical health and in delaying cognitive impairment (Faieta et al, 2021). There is also evidence that physical activity is a protective factor to dementia (Llamas-Velasco et al, 2015). Academic reviews have measured the possibility of exercise as a form of neuroprotection, with evidence supporting the development of structured exercise activities over a longer time-period (Kirk-Sanchez and McGough, 2015). The foundation of Dementia Actif is focused on providing social and exercise support, in the aim of reducing social isolation, loneliness and the impact of cognitive impairment for PLWD and unpaid carers. There is limited guidance on the standards of care and support for PLWD, around improving physical and cognitive functions. The UK Chief Medical Officers' Physical Activity Guidelines (2019) recommends weekly exercise of 150 minutes of moderate exercise or 75 minutes of vigorous intensity exercise for older adults. The Alzheimer's Society suggests gardening, indoor bowls, dance, seating exercises, swimming, walking and Tai Chi as activities for adults with early to middle stages of dementia (Alzheimer's Society, www.alzheimers.org.uk/get-support/daily-living/exercise/early-middle-dementia). The following section will focus on evidence-based themes on the potential benefits of interventions and activities for PLWD.



4.2.2 Benefits of Interventions and Activities

There is no evidence from the literature sample that exercise is detrimental to the wellbeing of PLWD. The consensus is that exercise can be recommended to support the overall wellbeing for PLWD (Begde et al, 2022). In fact, there is convincing evidence that exercise improves physical health, with promising evidence of improvements in cognition, primarily for people with mild to moderate dementia. There is less available evidence on the impact of exercise and activities on psychological wellbeing and behaviours (Lewis et al, 2020).

Liu et al (2022) completed a systematic review which found that physical activity and exercise has a positive impact on physical function, mobility, and activities of daily living. The findings also state that the available evidence is insufficient to support the conclusion that physical activity improves cognition for PLWD. An earlier review completed by Forbes et al (2015) also highlighted the challenges of measuring the impact of exercise of the quality of life for PLWD but also on the wellbeing outcomes for unpaid carers. Despite this finding, the work of the Dementia Actif Service has demonstrated drive and innovation in designing a plethora of methods to measure both the impact and the outcomes of their broad menu of activities.

Measuring the preventative impact of social activities and exercise on services is also a challenge, in particular the potential cost avoidance for Health and Social Care Services. Exercise and community activity-based programmes can be implemented in a cost-effective manner and on a community wide basis. Hartfiel et al (2022) completed a Social Return on Investment (SROI) to measure the social value and cost effectiveness of a home-based supervised exercise programme (PrAISED – promoting activity, independence, and stability in early dementia). The evaluation concluded that social value was gained from improved physical activity, increased confidence, more social connection, reduce strain on unpaid carers and less use of Health Services. The SROI ratios ranged from £3.46 to £5.94 return for every £1 invested, reflecting the potential impact and outcomes for people living with early dementia. This is of particular importance when considering that dementia is an incurable and a progressive degenerative disease. Whilst there is no cure, medication has been used to stabilize cognitive impairment, but often at the expense of adverse side-effects (Cassuriaga, Feter and Rombaldi, 2021).

4.2.2 Effective Interventions and Activities

As discussed, there is evidence of the positive impact of activities and exercise on the wellbeing of PLWD. More specifically, the evidence suggests that multicomponent exercise programmes, with a mixture of cognitive, physical and multi-tasking exercises are the most effective in improving walking, balance and visual processing (Bedge et al, 2022). Lam et al, (2018) also evidenced the benefits of multimodal exercise with a combination of resistance, aerobic, balance, flexibility and functional training. These are all features observed as part of the Dementia Actif activities.

The analysis of the literature sample highlighted varying guidance on the frequency, intensity, type, and time (FITT principle) of physical activity that could benefit PLWD. Lewis et al (2020) advised of the importance of clearly defining FITT dosage of exercise, as this is a key factor that impact on wellbeing outcomes. The type of intervention varied from study to study, and the intervention period also ranged from weeks to a year. The guidance around dosage and timing is around 60 mins a day, 2–3 days a week (Lam et al, 2018). Multimodal exercise that involves aerobic, balance, muscle, and flexibility training were the most frequently (Marcos et al, 2022). The overall findings indicated that multimodal exercises have

indicated functional benefits, including gait speed, walking endurance, balance and improved muscle strength for PLWD. The best evidence synthesis completed by Lewis et al (2020) found substantial evidence to support the role of exercise in improving activities of daily living (ADLs) and other physical outcomes, including grip strength, walking speed, time-to-stand, mobility, balance, cardiovascular fitness, strength, flexibility, balance. These key categories provide a potential outcomes measurement framework for Dementia Actif to quantify physical outcomes and to complement their use of the time-to-stand measure. As mentioned, despite the clear findings and measurements for physical outcomes, there is limited conclusive findings in the literature sample around the impact on cognitive function, psychological and behavioural symptoms, illustrative a gap in global research.

There has also been consideration in the evidence of the venue for the exercise classes, primarily homes-based and community-based venues. Whilst there were no findings that home-based exercise has any negative impact, the evidence demonstrated the added benefit on the quality of life when exercise is fun and includes social interaction (Bowes et al, 2013). Structured physical activity, if appropriately designed, can accommodate the needs of PLWD across diverse lifestyles (Faieta et al, 2021).

Chadwick et al (2022) completed an UK based, qualitative study on the impact of bespoke dementia friendly exercise activities for PLWD and unpaid carers. The study evaluated weekly exercise sessions facilitated by a Charitable Trust in a leading sports venue. The findings demonstrated both the physical and social benefits of exercise activities. A key benefit of the bespoke sessions was in reducing social interaction, due to the understanding of needs and the informal support offered to unpaid carers. The evidence highlighted that without these sessions it would not be possible for PLWD or unpaid carers to participate in physical exercise activities. These are messages echoed within this evaluation of the benefits of Dementia Actif activities as a space that allows and grows a mutual understanding on living with dementia.

Long et al (2020) completed an UK based mixed methods study of dementia friendly exercise class for PLWD. The exercise classes evaluated as part of this study are led by a physiotherapist and trained volunteers. The framework for the class is underpinned by positive support, a rehabilitative model developed by Clare (2017). The key principle of this model is a focus on person-centred and positive rehabilitation that includes the presence and support from unpaid carers. There is key learning offered by this study, including a specialised dementia friendly exercise class structure, focused on:

- Consistent structure of a 1-hour long class.
- Five-minute warm-up focused on cardiovascular work (e.g., marching and running on the spot).
- Small group (two to six participants) exercises across six-station circuit, completed for one minute and repeated twice.
- Each circuit station features the same exercise each week, which can be completed at different levels, depending on individual physical capability, and personal progress.
- Exercises include squats, step ups, bicep curls with weights, push-ups, boxing, and shuttle runs.
- Each station is completed for one minute before moving to the next, until a full circuit is completed.
- A timed five-minute break encourages participants to have a glass of water, before the circuit is repeated.
- Unpaid carers are encouraged to support the PLWD.
- The class finishes with 10-min instructor-led balance exercises, including static and dynamic postures (e.g., tandem walking, backwards walking and single leg stands).

The feedback on the venue and class structure revealed the following factors that PLWD and unpaid carers appreciated as part of a dementia friendly activity:

- Accessible parking.
- Access to toilets.
- Socialising over a coffee after the class.
- The knowledge and support of staff members and volunteers.
- Bespoke classes for PLWD, which allowed unpaid carers to participate.

(Cited from Long et al, 2020)

The feedback from Long et al's study echoed the voices and views shared by the Dementia Actif participants, with the Dementia Actif Team members facilitating classes and activities with these key factors in mind.

Another UK based study measured the impact of a 12-week ThinkingFit programme (Dannhauser et al, 2014), which consisted of three activities: physical activity, group based cognitive stimulation training and individual cognitive stimulation training. The physical activity phase included 30-45 min physical activity sessions per week at moderate heart rate intensity, including a structured pattern of walking which was measured through a validated scale. The second phase, the cognitive stimulation training took place in groups of around eight participants, with weekly 2.5 hours sessions focused on adult education classes in arts and crafts. The broad range of tutor led sessions ranged from pottery to genealogy, with a focus on sensory and diversifying sessions to maintain interest and stimulation through the Lumosity that offers different games and puzzles. The findings from this study and the evaluation of the 12-week programme indicated two key points of interest and potential application to the Dementia Actif Service. Firstly, the high recruitment levels due to low pre-existing levels of physical activity and secondly, the impact and improvements in physical fitness and cognitive outcomes. Outlined in the box below are other identified bespoke dementia interventions from Canada and the USA.

Minds in Motion Minds in Motion® program

<https://alzheimer.ca/on/en/help-support/programs-services/minds-in-motion>

<https://www.youtube.com/watch?v=3dkKquMiQIk> Silver Sneakers program

Based on the review of this literature sample, which includes high quality systematic and meta-analysis reviews, health and social care practitioners should feel confident in promoting access to Dementia Actif, due to the benefits of exercise, social activities and the positive impact of dementia friendly interventions on the quality of life, wellbeing and selfhood of PLWD and unpaid carers.

4.3 Summary

Despite the key message of the importance of activities, as both the physical and cognitive protective factors, there continues to be limited global guidance of the use of physical activities or exercise as a form of social prescription to delay or potentially prevent the symptoms of dementia. As a result, Cassuriaga, Feter and Rombaldi (2021) recommended as part of their global research that further work should be undertaken to inform guidelines on physical activity for PLWD. Following specific guidelines and a bespoke exercise programme may be of benefit to the Dementia Actif Service.

The review reflects positive findings around the impact of exercise and social activities on the wellbeing of PLWD and unpaid carers. The findings consistently support the benefits of physical activities on physical wellbeing and function, whilst the evidence on the impact on cognitive and emotional development is limited. Despite this, the evidence demonstrating the positive effects of physical activity interventions on cognition is robust (Groot et al, 2016; Forbes et al, 2014). The findings across the literature sample illustrated the potential of dementia friendly physical and social activities as a community wide and cost-effective intervention that benefits the wellbeing of PLWD and unpaid carers. As a form of social prescription, the menu of choice of activities offered by Dementia Actif can continue to develop and grow as both an alternative and add-on to clinical and pharmacological treatment. This is further amplified when considering the cost and potential adverse side-effects of medication, in comparison to the potential social value of physical activity. It is also of importance that across all the studies reviewed, there were no reported negative aspects of physical or social activities on PLWD or unpaid carers. Park and Cohen (2019) reported that exercise has a positive effect on physical health and psychosocial well-being.

Physical and social activities that are dementia friendly and bespoke to the wellbeing needs and outcome of PLWD function as a protective factor, which highlights both the demand and need for Dementia Actif and healthy wellbeing plans for PLWD and unpaid carers.



5. Findings and Discussion

5.1 Workstream 2: Interviews/focus groups with professional stakeholders, PLWD and unpaid carers

This section outlines the key findings from the qualitative data analysis, which gathered the views and perspectives of professional stakeholder, PLWD and unpaid carers. Semi-structured interviews and focus groups were conducted over Microsoft Teams, were audio recorded and transcribed verbatim and the data anonymised. As this was a local study based in Gwynedd, the sampling composition focused on professional staff members working on a multi-agency basis with Dementia Actif. The interviews and focus groups ranged in length from 30 minutes to 70 minutes. There was positive agreement to participate in the evaluation on a multi-agency basis. A broad range of professional staff members on a practitioner, middle and senior leadership level agreed to participate, with some contacting me directly to express a wish to participate in the interview. The sample included professionals from Adult Social Care, Betsi Cadwaladr University Health Board, Alzheimers UK, Byw yn Iach, Public Health Wales, external providers and Gwynedd Councillors (n=14). Due to the specialist or individual nature of roles and responsibilities of each participant, it is not possible to include specific job roles in order to protect the anonymity of all participants.

The interview schedule closely linked to the research questions, objectives and the themes identified from the findings of the rapid literature review. The interviews focus on exploring in detail the multi-agency understanding of Dementia Actif, focused on exploring the nature of the service and support provided, including the uses and limitations of this service. The discussion also gathered the views on future development. Interview transcripts were individually analysed a thematic approach (Braun and Clarke, 2006).

A list of key themes was identified for each participant, which was then cross-referenced to produce a recurrent themes Table for the whole sample. The interview transcripts were explored in detailed, with a thematic analysis completed of each transcript. The analysis of each theme will be discussed in a thematic summary of the views gathered across the interviews. A review of the interview and focus group transcripts informed the identification and development of four themes:

Theme 1: Preventative support

Theme 2: Support for unpaid carers

Theme 3: Funding

Theme 4: Future developments.

Each theme will be discussed separately to inform the overall evaluation recommendations.

Theme 1: Preventive Support

Participant 1 started the interview with a clear discussion around the concept of keeping active and the potential impact on pressures on other services across health and social care.

"But for me, I think that the name Dementia Actif, or just keeping active, means that people can carry on in with their lives before needing statutory services. We all know about the shortage of carers, shortage of services, major financial problems in the local government but also in the health service." (P1)

Participant 1 developed this discussion with consideration of the nature of this problem, by explaining:

"I think they [Dementia Actif] fill an obvious gap, of course, specifically with dementia. And dementia is going to increase. We were looking at demographics and figures the other day. So specifically, they help people with dementia, and then, of course, through that they help carers. But more generally for the citizens of Gwynedd, as we all pay council tax, and I think that the preventive work they do, supports the health service. If you can keep people out of the hospital, back in their communities, that will be the case for all the citizens of Gwynedd, I say." (P1)

It was also explained that this support can be offered prior to formal diagnosis, which can understand and support for families during challenging times:

"Support can be offered before a diagnosis. If someone is quite active to start with and they're keen to keep that going, or a family says, 'Oh, we'd love it if there was somewhere where...' Well, it's more than just keeping fit and dancing, isn't it. It's just that contact and the peer support, that there is someone else there who also understands what they are going through." (P5)

The impact on wellbeing was described as keeping active but also around cognitive stimulation, as described by Participant 13 following their review of the case studies gathered by Dementia Actif:

"The cognitive stimulation, you know, the more things that people are able to do to keep active, it helps, you know, their health and well-being as well. And the importance of testimonials is clear." (P13)

Participant 1 also discussed the impact on wellbeing across a diverse community:

"So, I think this thing of being active is just so important [as medical interventions]. And something that facilitates that for people with dementia but also for carers and everyone in society is really important." (P1)

Participant 5 described that the referral process to access support is 'user friendly' and accessible:

"And I just compare other places where you have a referral form you have to fill in with a list of medication, blood pressure, weight, and you just think... it's about people going there." (P5)

The preventative work around education and raising awareness was also highlighted as a key aspect to the preventative work, to create spaces that can support Gwynedd families, as summarised by Participant 11:

"I think you know it's all about sort of that myth busting and raising awareness and creating those supportive environments. That's all being part of the vision from the start I think and utilizing communities and then you know also dispelling myths. This is something that happens to people, that actually prevention can happen early on in life. And the earlier the better." (P11)

The reach of the awareness raising, support, activities and training was also seen as being delivered across Gwynedd. Participant 12 touches upon the reach and impact of the dementia friendly training delivered by Dementia Actif.

"We've got 250 staff and they've all had access to Dementia Actif training, which hopefully makes our sites much more welcoming for the population." (P12)

The attraction of Dementia Actif, the social and fun element was highlighted as a key aspect that kept people engaged in the activities on a long-term basis.

"I think from my point of view the importance of providing fun. It needs to be a fun session, enjoyable session, and obviously there's more people getting diagnosed dementia at a younger age. So, it's not just for the elder community and just reaching out, you know, and the idea behind what was done with the tea dance, it gave Emma and the team, you know, the opportunity of speaking with people." (P14)

This was a message shared across some of the interviews, with a similar view shared here by Participant 1:

"I have seen them on a journey...they are [Dementia Actif] just brilliant. Everything that they do, the relationship with older adults, and the fun. On a superficial level it appears as fun, but there's a lot of thought and preparation behind the scenes." (P1)

This also identified that Dementia Actif can support the broader community of PLWD and unpaid carers, building a sense of connection. Participant 11 takes this a step further and conceptualises this sense of connection through the Dementia Actif community as a spider web, positive infectious disease, and a community with a role for everyone.

"The Connectivity.... the team have been very successful at building that web. Like if they're the spider in the middle, they've actually linked so many services, so many individuals, so many lives and families, into this way of thinking, they have actually brought people along with them and it's about sort of how... I'm using sort of all kinds of terminology here, but they they've almost been able to infect society in Gwynedd with the knowledge and the understanding of dementia and where it is, who it affects. And they've created those relationships, as not one bit of the system can help to ease this situation alone. It's about that connectivity and everybody playing whichever small bit they can." (P11)

The demand and potential for growth of preventative services was described as a key aim around the drive for development through new funding streams.

"So, I think we've got quite a multifaceted relationship with Dementia Actif, but it's definitely one that we value, and we'd really like for it to grow even further in the future. We're big fans, we promote the activities.... the only thing is that they need more resources." (P12)

With the potential benefit of the growth of the service described as being far reaching, when agencies work in partnership together to support the preventative activities.

"But all communities benefiting from physical activity. And we have a real clear recognition that we can't do that on our own and we'll never have the resources to be able to reach every single person and every community. So, working in partnership with organizations such as Dementia Active Makes Perfect Sense for us because it gives us that." (P11)

The community ethos around living well with dementia was discussed and the potential alternative without Dementia Actif:

"It's the idea of living well with dementia.... or somebody has a diagnosis and there we go. It's kind of downhill and very gloomy where there's this kind of approach." (P1)

The rationale for the preventative development was fully attributed to the Dementia Actif staff team, described as,

"The kind of people, they're skills, their ability to connect and to make those connections." (P12)

"The team and the strength of the team, you know, that they enjoy, love, delivering the sessions supporting people in the community. And I'm gonna use 3 words 'making a difference'. You know, that's what they're doing. They're making a difference to the lives of so many people. And in in Gwynedd." (P14)

There was also a focus on the leadership offered by Emma Quaeck and the positive impact this provides to the team and ultimately to Gwynedd citizens.

"I think we can't avoid the 'Emma factor' in the middle of all this. I think it's just her enthusiasm as an individual and the effect she has on the team, and as a result the enthusiasm of the team." (P3).

Whilst the quality of the team as whole unit was also acknowledged, *"and where Emma is lucky, the team she has is quite a good team."* (P10) The team were described as effective (friendly!) spiders that weave a community web of preventative support. The pride in this Gwynedd led innovative services was clear across all the interviews and focus groups.

"It's interesting that Gwynedd have done something quite innovative. We need to do more to bring that to the attention of the people of Gwynedd themselves and to praise that and to have a little bit of pride." (P1)

With Participants 2 and 6 adding their views and also their admiration:

"The work the team is doing is amazing.... it's so positive. I can only admire them. And they won awards in Gwynedd, didn't they, so that says a lot to me." (P2)

"I think Dementia Actif is fantastic. It's reflected in how many people attend. Everything that they do, it so successful, so that is testament in itself, I think" (P6).

The overall benefits of Dementia Actif was attributed to the professional and friendly foundation provided by all the team members. This ensured that families accessed the Service, enjoyed and benefited from the activities, as Participant 5 explained that the approach offered by the team, *"hooked them [PLWD and unpaid carers] in and keep them in, to experience Dementia Actif!"*

Theme 2: Support for unpaid Carers

The second theme identified from the thematic analysis was focused on the support offered and provided to unpaid carers. Advice was provided that activities should focus on *“the caregiver and how Dementia Actif is integrated into the Community”* (Participant 13). There was a sense of empathy and understanding around the impact on unpaid carers, in particular the pressures of caring responsibilities.

“We need to care for the carers, you know, there are a lot of figures over recent years, reflecting the overwhelming numbers of unpaid carers. Unpaid carers provide savings to statutory services. To be honest, they [unpaid carers] are the best people to care, as they truly do care, you know” (P1).

The support to unpaid carers was also seen as filling a gap and addressing otherwise unmet needs, and often stigmatised needs during uncertain times.

“There is that gap between knowing that there is something wrong and being diagnosed, and that middle part, where does one go? They don't know what's going on. They care. And these conversations, where they can talk?” (P8).

The skills, person-centred and relationships-based approach to the support provided was also described:

“So, they [Dementia Actif] give empowerment first to help people open up. Oh, just encourage, encouragement, positive encouragement. They provide information because some don't know anything about what they have, you know, what kind of dementia they have or what to expect or what not. If there is someone who doesn't get the diagnosis or the carer doesn't know which way to go, they share, so the companionship, the peer support they get. A key part of Dementia Actif is the carers' group. Oh, it's so important that a carer gets that information, gets to share their feelings in somewhere safe.” (P9)

There was also acknowledgement of the flexible, online support offered by dementia Actif throughout the global pandemic:

“The Dementia Actif support during COVID kept in relentless contact with people, during this difficult and gloomy time.” (P5)

Dementia Actif was described as a space for PLWD and unpaid carers. Participant 5 described the support as *“something out there that makes life a little bit richer and normal during difficult times.”*

Theme 3: Funding

The third theme focuses on the discussion around funding arrangements, in particular the views of participants on future funding arrangements to grow and develop the Dementia Actif Service. Participant 12 provides a firm view on this point, in particular that Dementia Actif should be seen as a strength-based service:

"Why aren't we shouting louder about the fact that this should have quadruple the amount of resource in it? You know, a few weeks ago services were saying that people need to take more responsibility for their well-being, to take the pressure off the health service. This is it!" (P12)

There were also words of advice and guidance to the team:

"Accepting the fact that you cannot be all things to all people, all the time. So, I think there may be something there in that you can stretch yourself too thin and burn the team out and then your no good to anybody. It's better sometimes to consolidate, regroup and really put your energy into where you're having that impact with people." (P11)

There was acknowledgement that the Dementia Actif team members have been proactive in bidding for grant and short-term funding. However, there was a view that this caused uncertainty, stress and additional work. Participant 9 shared their view on this point:

"I think that Emma has done everything that she can. I think they need more funding. I think it should be forefront in all areas of Gwynedd. Dementia Actif is not just a bit of fun and exercise. Dementia Actif is an integral part of people's support network. They tick all the boxes!" (P9)

There was also a sense that this service aligned perfectly with the guidance outlined in Welsh policy (e.g. Healthier Wales, SSWA etc) and should therefore be integrated as part of the core funding of Adult Services.

"Somewhere somehow there should be someone who leads in the Council that should be motivated to fight for those additional resources. We have all [the focus group] said I don't think there's anything wrong with what they do. I struggle to know what they should do differently. They just need to do more of it and have the resources to be able to do more of it, don't they?" (P12)

As an observation, there was a passion and commitment by all participants to voice their views on funding arrangements, advocating in a supportive and protective manner. As an experienced researcher, I have not previously observed this form of support, across diverse stakeholder services. When discussing the potential limitations of Dementia Actif, there were no comments or suggestions around either areas of concern or arrangements that required changing. The only limitations shared was the lack of long-term core funding to support a vision around continued service development in this area. Indeed, this recommendation was shared across all interviews, focused on investing in a preventative service to support families who live with an incurable disease that is growing at a rapid pace.

Theme 4: Service Development

There is evidence from the analysis of the progress reports that the voices of PLWD and unpaid carers has been central to all Dementia Actif developments. Participants shared that this should continue, as should the developments based on the ethos that there's *"something for everyone"* (P6). There was a sense that Dementia Actif is a 'loved' Service, as described by Participant 6:

"And the number of people who, when talking about Dementia Actif, were basically saying, "I love them. They have changed my life." And I think that has to be the crux of it."

Participant 2 also suggested that regular contact with the communities across Gwynedd should continue:

"That there is more of it [Dementia Active activities]. That there is more contact with communities, parish councils, town councils, and that there is more involvement with them, and not just the council, to bring attention, especially the community councils and small-town councils." (P2)

There were suggestions offered around planning, due to the need to align service delivery with the needs now and to the future (as profiled in the Population Needs Assessment).

"I think this is so important that sort of integration into the mainstream and that goes for future funding as well because we've been profiling the populations health and well-being in North Wales recently. And obviously there's a Gwynedd profile and that shows obviously like many other areas, we've got an ageing population, the prevalence and incidence of dementia is only going to grow." (P11)

Gwynedd is a vast county, therefore understanding the needs across the area, including the challenges of meeting the needs in different areas is crucial to both the strategic and operational planning of services. Participant 7 helpfully suggested the need for a clear service vision, focused on planning over a 5-year cycle. Planning appropriately can also scope gaps in services, and identify other services across the county that can link in with Dementia Actif activities. Robust planning will ensure that there is questioning on:

"How did we decide where to set services? Is it due to the availability of a building etc? Or was it due to genuine need: look we have evidence of the need here. There is a gap in service delivery in this area."

Participants shared the view that further research and robust outcomes measures would further serve the growing evidence base of the impact of Dementia Actif. Participant 2 suggested that *"we need to be able to show what could have happened in a parallel universe if Dementia Actif did not exist."* (P2)

A larger scale research project, with a focus on a Social Return on Investment would assist to achieve this aim. The overall key factor around development came back to funding:

"I just want to give them loads of funding really to grow it, to keep it going so that more people can access it." (P6)

There was also the need to succession plan and develop the team now and to the future, as explained:

"The one thing you can't teach is the passion and the personal experience that Emma brings to it. But there will be people out there because this is something's gonna touch all of our lives at some point. So yeah, I agree that there is a risk and something needs to be put in place to mitigate that." (P9)

The participants voiced their confidence in the service, in particular the ability of all the Dementia Actif team member to develop, respond to changing demography and needs.

5.2 Workstream 3: Observation of Activities

Observational data was collected overtly by the researcher who took part in the activities, who made notes during breaks in the sessions and at the end of the sessions. This enabled the researcher to immerse herself in the activities and experience them in the way that participants did in addition to providing context and a rich understanding of how it felt to be part of the group.

The researcher observed and took part in five key activities:

The DEEP conference in Plas Tan y Blwch

On the 28th of June 2022, the researcher attended the DEEP conference held at Plas Tan y Blwch. This was a multi-agency event, led by the DEEP network, the UK network of dementia voices. This conference was the Dementia Loud and Proud event, to celebrate the 10 year anniversary of this network. The aim of attending this session was to gather a sense of the role of the Dementia Actif Service.

Session 1 on the programme was led by Dementia Actif. This session focused on exercise movement, which was friendly, fun and vibrant. The session was led by an experienced member of the Dementia Actif Service. There was a clear structure and focus to the session, which was inclusive and adapted to needs of those attending. The flexible nature of the session was clear from the start, with guidance offered on alternative movements for each exercise. The music and friendly guidance inspired a session that was driven by fun and laughter, within a space that included professionals, PLWD and unpaid carers.

The feedback from the session was positive, with those attending sharing their enjoyment and appreciation at the end of the session. The conference programme included a variety of workshops, including mindfulness, arts/crafts, music and discussion spaces around the value of support. The Dementia Actif Service were visible throughout the day in providing support, leading on various sessions and understanding the broad needs of those attending the event. Three key themes were apparent from the observations of the event: firstly, the knowledge, understanding and skills of the Dementia Actif staff members, secondly, the established and rich relationship the Dementia Actif Service have established with a broad range of multi-agency professionals and finally, their understanding of the community and the needs of PLWD and unpaid carers.

The online unpaid carers session

On the 29th of November 2022, the researcher attended the online session for carers. The session was attended by four carers, who attended this forum on a regular basis. The structure, pace and flow of the session was dictated by the carers. The Dementia Actif facilitator offered a space that was focused on listening and offering support, which the participants shared was of value to them to reduce the stress and pressure of caring on an everyday basis for their family member who is living with dementia.

The participants shared their views around some of the challenges they were experiencing and voiced the benefit of having a peer forum, where others could understand their experiences without feeling stigma, shame and a general lack of understanding. They openly discussed Dementia Actif as their 'lifeline', with those attending the session sharing their support for each other throughout the discussion. It was apparent that this forum had supported and facilitated a support and friendship network for carers, that was shaped by the voices and experiences of those attending the forum.

A 30-minute online exercise class

The aim was to attend an online Dementia Actif exercise session to participate and observe. On the 24th of April 2023, the researcher attended a 30 minutes online exercise class. A broad range of PLWD attended the class, including individuals living in the community and people living within residential homes across Gwynedd.

The bilingual introduction to the session was friendly, clear and concise. A check-in with everyone attended was facilitated at the start of the session, in a natural and inclusive manner. The empathy, understanding and communication skills of the sessions leader was apparent and should not be under-valued. These skills were clearly based on years of experience and expertise, illustrating the importance of relationship based support.

The session followed a clear structure, with a warm-up, main exercise and cool-down sections. Each movement was explained, with alternative movements offered and guidance provided for everyone to participate at their own pace and comfort. Each movement was explained, with the link to the body part, including explaining the benefit of each exercise. Therefore, the function and benefit of each movement was weaved into the session in a seamless and accessible manner. At the end of the session, all participants shared their enjoyment and noted the positive impact on their wellbeing, from a physical and emotional perspective. This session also illustrated the possibilities and benefits of online sessions, which reduced the need for travel but continued to offer a space that encouraged social interaction and connection.

A face-to-face exercise session in Caernarfon

On the 27th of April 2023, the researcher attended and participated in a face-to-face Dementia Actif exercise class, held at Caernarfon Leisure Centre. This is a suitable and accessible venue, with excellent parking facilities. The Dementia Actif lead was encouraging, professional and kind throughout the session. It was apparent from the outset that she has robust and detailed knowledge of the needs of all the participants. The leadership offered by the Dementia Actif instructor developed an inclusive space, that offered something for everyone. This session included 26 individuals, with a mixture of PLWD and unpaid carers. Class participants attend on a regular basis, with the benefit of regular attendance illustrated in the positive relationship of participants with the instructor.

Again, the class was clearly structured, with the introduction offering everybody a 'check in' before starting the physical movements. Each movement was explained, with alternative movements/exercise offered to cater for individual needs. The session also offered a social space, with time for refreshments. Participants voiced their appreciation of the Dementia Actif sessions, in particular the physical, emotional and social benefits felt at the end of each session. This is also apparent in the attendance and demand for the courses, which is consistent throughout the year. Participants also shared the preventative benefits of the support, clearly stating that this support offered them respite and the connection with the community that they would otherwise not be able to Access.

The Porthmadog Boccia League

On the 5th of May 2023, the researcher attended and participated as part of the Gwynedd Boccia League, facilitated by the Dementia Actif Service. As part of the session, 16 teams participated from a variety of services across Gwynedd, including the learning disabilities services. The atmosphere was focused on fun and competition, in a spirited and inclusive manner. The researcher joined a Boccia Team and benefited from listening to the views of those involved. There was a sense that having this involvement with the Boccia league on a monthly basis, provided purpose and social involvement, that most would not otherwise benefit from. All participants shared their views of the Dementia Actif team members, voicing their respect and deep connection with all the team members. This was also observed throughout the social interactions, demonstrating the relationship between participants and Dementia Actif. Several participants also noted that a reduction in activities offered by Dementia would significantly impact on their wellbeing and ability to maintain a link with their community, which they shared benefitted their overall physical and emotional wellbeing.

All the activities observed consistently demonstrated the connection between Dementia Actif and several communities across Gwynedd. It also highlighted the benefits of the knowledge and experience of Dementia Actif, including the benefits of offering and providing relationship-based activities which developed on community assets in a strength-based manner.

6. Conclusion

This section offers a summary of the main findings and learning points from this evaluation.

The contribution of Dementia Actif: This small-scale project has developed to be a comprehensive and valued service for citizens across Gwynedd. The sustained work and effort to achieve this type of growth should not be underestimated. The service development has focused on weaving a web of valued activities that align perfectly to the strength-based social policy vision for older people across Wales.

Measuring Outcomes: Dementia Actif has been innovative in constantly developing methods to measure the impact of this provision. The voices of PLWD and unpaid carers is felt throughout all the service developments, with case studies collected on a regular basis to understand people's experience of using this service. Whilst the living experiences of PLWD and unpaid carers are captured in the case studies, the Dementia Actif progress reports also monitor the data and income generated. When considering that Dementia Actif started as a small-scale project, the thought and consideration given to the development of the outcome measurements should be applauded. The service is now in a good position to plan for future developments and create a robust outcome measurement framework.

The Impact of Dementia Actif: The evidence gathered for this evaluation clearly demonstrates that Dementia Actif is exceeding the original vision and aim, with constantly increasing citizen participation across all activities offered, on a Gwynedd wide basis. The activities are delivered by skilled and passionate staff members, all working as a team. The personhood of all participants of the Dementia Actif activities are promoted in a person-centred and strength-based manner. Activities are adapted to meet the individual needs and abilities of those participating. Unpaid carers are also supported, sharing how valuable this support is in meeting their overall wellbeing, again in a preventative and strength-based manner.

Future Developments: There is overwhelming multi-agency support for the growth and development of Dementia Actif as a long term, core funded service. The findings indicate the positive impact of an active/wellbeing model for supporting PLWD and their carers, in particular the use of preventative community-based resources and activities. This reflects the low-cost benefits of social activities on overall wellbeing outcomes, including giving PLWD and their carers voice, choice and control over their own wellbeing outcomes to connect them with their community.



7. Recommendations

Policy and Strategy: Recommendation 1: The completion of a financial bid that secures long-term, core funding for the Dementia Actif Service. Dementia Actif should be fully funded as part of the core and mainstream services, which will improve long-term planning.

Policy and Strategy: Recommendation 2: The development of a Dementia Actif five-year plan focused on key priorities, marketing, financial modelling (including income raising) and healthy wellbeing for PLWD and unpaid carers.

Practice Development: Recommendation 3: The development of Dementia Actif baseline and follow-up outcomes measures focused on quantifying physical impact (strength, flexibility, gait, balance, mobility, walking endurance, dual-task ability, activities of daily living, quality of life, and falls), cognitive function (language, attention, memory), emotional/psychological wellbeing (depression, mood, quality of life) and behaviour (agitation, sleep pattern, wandering). These measures to be informed by validated scales, to design Dementia Actif bespoke measures that can be co-produced with PLWD and unpaid carers, and piloted/tested prior to implementation.

Practice Development: Recommendation 4: To develop the menu of choice of activities underpinned by person-centred support and the principles of the positive support model of rehabilitation. The development of the physical activities to by the FITT principles around dosage and by dementia friendly class structures.

Research Development: Recommendation 5: The potential of using this evaluation to inform the development of a larger scale funding bid, which could fund a larger scale research project focused on developing validated measures and completing a Social Return on Investment to measure the social value and cost effectiveness of the programme.



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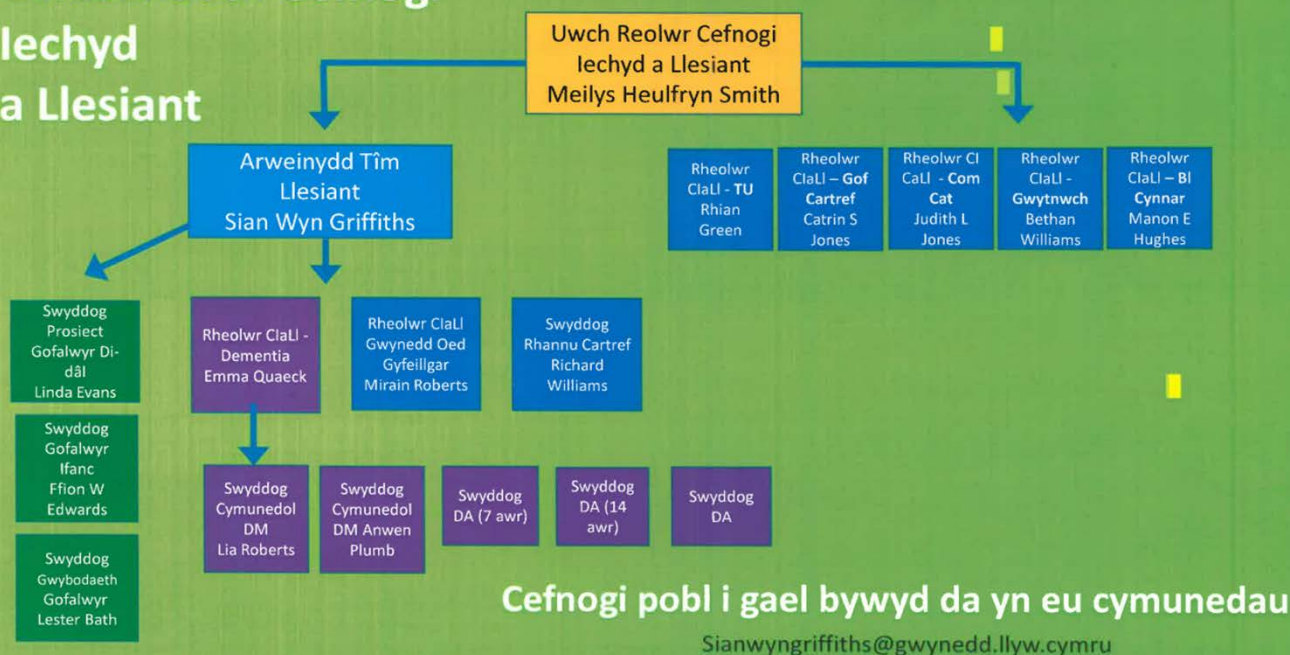
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Appendices:

Appendix 1: Service Structure

Gwasanaeth Cefnogi Iechyd a Llesiant



Appendix 2: Project Information Sheet

Evaluation of Dementia Actif: Gwynedd County Council

Gwynedd Council is funding Bangor University to undertake an evaluation to explore the things that work and the things that need to be developed with the Dementia Actif Service.

Bangor University will be using information provided by you in order to undertake this evaluation, this means that we are responsible for looking after your information and using it properly.

You will be invited to take part in an online evaluation interview or focus group. This will be through Microsoft Teams or can be over the telephone, whatever feels best for you. If you change your mind about taking part in the interview or focus group, that's OK, your answers can be removed from the evaluation up to six weeks after you complete the focus group/interview. There are no right or wrong answers to the questions I will ask you, I will only ask you about your views on the Dementia Actif Service. It's important to note that your choice to take part in this evaluation is totally voluntary.

The evaluation interview or conversation will take place over the phone or over the computer (if you feel comfortable) in February/March 2023 and will take around 1 hour. This conversation will be confidential, with the researcher (Ceryl Davies) conducting the interview over the phone or computer in a private room (no one else will be able to listen to our conversation). If you are happy, this conversation will be recorded and then typed up by an approved transcriber (a person who works to type up these types of conversations). If any names are noted during our conversation they will be removed from the record, so that it will not be possible to identify individual people.

I hope that taking part in this evaluation will give you the opportunity to share your views and experiences, with the aim of developing the Dementia Actif Service. I understand that taking part in these conversations is usually interesting and enjoyable.

I shall take the following steps to keep your information confidential:

- 1) Personal information you provide will **not** be shared with anyone unless a safeguarding concern is identified.
- 2) All information will be noted in a way that doesn't mention any names.
- 3) I will make sure that I keep your information safe, and I will follow legal rules (the Data Protection Act 2018).
- 4) I will share a copy of the draft report with you. You can share your comments on the draft report. After the final report is completed, I can share a copy with you if you wish.

The only time I **must** share information is if you tell me anything that makes me worry about someone being in trouble or being hurt (which is called a safeguarding concern). I will have to share this information with the relevant officer at Gwynedd Council, which has been identified as the Well-being Manager.

If you want to have a chat about this project, please contact me/ Ceryl Davies on 07887888991 or via email ceryl.davies@bangor.ac.uk

If you wish to raise a complaint on how I have handled your personal data, you can contact our Data Protection Officer who will investigate the matter. If you are not satisfied with our response or believe we

are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO). If you require further information, our Data Protection Officer (Bangor University) is Lynette Williams and you can contact her at Email: l.d.williams@bangor.ac.uk or Phone: 01248 388530 if required.

If you wish to discuss any queries or concerns about this project with Gwynedd Council, please contact Emma Quaack, Dementia Actif Manager on emmajaynequaack@gwynedd.llyw.cymru

Gwerthusiad o Dementia Actif: Cyngor Gwynedd

Mae Cyngor Gwynedd yn ariannu Prifysgol Bangor i gynnal gwerthusiad i archwilio'r pethau sy'n gweithio a'r pethau sydd angen eu datblygu gyda'r Gwasanaeth Dementia Actif.

Bydd Prifysgol Bangor yn defnyddio gwybodaeth a ddarperir gennych chi er mwyn cynnal y gwerthusiad hwn, sy'n golygu ein bod yn gyfrifol am ofalu am eich gwybodaeth a'i defnyddio'n gywir.

Byddwch yn cael eich gwahodd i gymryd rhan mewn grwp ffocws/cyfweliad gwerthuso ar-lein. Bydd hyn trwy Microsoft Teams neu gall fod dros y ffôn, beth bynnag sy'n teimlo orau i chi. Os byddwch chi'n newid eich meddwl am gymryd rhan yn y grwp ffocws/cyfweliad, mae hynny'n iawn, gallwch chi dynnu'ch atebion o'r gwerthusiad hyd at chwe wythnos ar ôl i chi gwblhau'r cyfweliad. Nid oes unrhyw atebion cywir nac anghywir i'r cwestiynau y byddaf yn eu gofyn ichi, ni fyddaf ond yn gofyn ichi am eich barn am y Gwasanaeth Dementia Actif. Mae'n bwysig nodi bod eich dewis i gymryd rhan yn y gwerthusiad hwn yn **gwbl wirfoddol**.

Bydd y cyfweliad gwerthuso neu sgwrs yn digwydd dros y ffôn neu dros y cyfrifiadur (os ydych chi'n teimlo'n gyfforddus) ym mis Chwefror neu Mawrth 2023 a bydd yn cymryd tua 1 awr. Bydd y sgwrs hon yn gyfrinachol, gyda'r ymchwilydd (Ceryl Davies) yn cynnal y cyfweliad dros y ffôn neu gyfrifiadur mewn ystafell breifat (neb arall yn gallu gwrando ar ein sgwrs). Os ydych chi'n hapus, bydd y sgwrs hon yn cael ei recordio ac yna'n cael ei theipio gan drawsgrifydd cymeradwy (person sy'n gweithio i deipio'r mathau hyn o sgysiau). Os bydd unrhyw enwau yn cael eu nodi yn ystod ein sgwrs byddant yn cael eu tynnu oddi ar y cofnod, fel na fydd yn bosibl adnabod pobl unigol.

Rwy'n gobeithio y bydd cymryd rhan yn y gwerthusiad hwn yn rhoi'r cyfle i chi rannu eich barn a'ch profiadau, gyda'r nod o ddatblygu'r Gwasanaeth Dementia Actif. Rwy'n deall bod cymryd rhan yn y sgysiau hyn fel arfer yn ddiddorol ac yn bleserus.

Byddaf yn cymryd y camau canlynol i gadw eich gwybodaeth yn gyfrinachol:

- 1) Ni fydd gwybodaeth bersonol a ddarperir gennych yn cael ei rhannu ag unrhyw un oni bai bod pryder diogelu yn cael ei nodi.
- 2) Bydd yr holl wybodaeth yn cael ei nodi mewn ffordd nad yw'n crybwyll unrhyw enwau.
- 3) Byddaf yn gwneud yn siŵr fy mod yn cadw eich gwybodaeth yn ddiogel a byddaf yn dilyn rheolau cyfreithiol (Deddf Diogelu Data 2018).
- 4) Byddaf yn rhannu copi o'r adroddiad drafft gyda chi. Gallwch rannu eich sylwadau ar yr adroddiad drafft. Ar ôl i'r adroddiad gael ei gwblhau yn derfynol, gallaf rannu copi gyda chi os dymunwch.

Yr unig amser y mae'n rhaid i mi rannu gwybodaeth yw os byddwch yn dweud unrhyw beth wrthyf sy'n gwneud i mi boeni bod rhywun mewn trafferth neu'n cael ei frifo (a elwir yn bryder diogelu). Bydd yn rhaid i mi rannu'r wybodaeth yma gyda'r swyddog perthnasol yng Nghyngor Gwynedd, sydd wedi ei adnabod fel y Rheolwr Llesiant.

Os hoffech gael sgwrs am y prosiect hwn, cysylltwch â mi/ Ceryl Davies ar 07887888991 neu drwy e-bost ceryl.davies@bangor.ac.uk

Os dymunwch wneud cwyn am sut yr wyf wedi trin eich data personol, gallwch gysylltu â'n Swyddog Diogelu Data a fydd yn ymchwilio i'r mater. Os nad ydych yn fodlon â'n hymateb neu'n credu ein bod yn prosesu eich data personol mewn ffordd nad yw'n gyfreithlon gallwch gwyno i Swyddfa'r Comisiynydd Gwybodaeth (ICO). Os oes angen rhagor o wybodaeth arnoch, ein Swyddog Diogelu Data (Prifysgol Bangor) yw Lynette Williams a gallwch gysylltu â hi yn E-bost: l.d.williams@bangor.ac.uk neu Ffôn: 01248 388530 os oes angen.

Os hoffech drafod unrhyw ymholiad neu bryder am y prosiect hwn gyda Chyngor Gwynedd, cysylltwch ag Emma Quaeck, Rheolwr Dementia Actif ar emmajaynequaeck@gwynedd.llyw.cymru



Appendix 3: Consent Form

Consent Form: Dementia Actif Evaluation.



Thank you for considering taking part in this evaluation.

I must explain the project to you before you agree to take part.

If you have any questions:- please ask me/Ceryl Davies (Researcher, Bangor University) before you decide whether to take part.



☎ 07887888991 or ✉ ceryl.davies@bangor.ac.uk

If you are happy, please tick each box below.	✓
I have read the information sheet for this project.	
I have had the opportunity to ask questions.	
I understand that I can decide to take part in this project.	
I understand that I can change my mind after agreeing to take part in this project without saying why.	
I understand that I can change my mind about taking part up to six weeks after talking to the researcher about this project.	
I understand that all my personal information will be kept confidential. It's only the researcher that will view this information.	
I understand that none of my personal information will be in the project report.	
I agree to be part in a focus Group/interview lasting no more than 1 hour. I agree to the focus group/interview being audio recorded.	

Name of Individual/Participant

Date

Signature

Ffurflen Cydsynio: Gwerthusiad Dementia Actif

Diolch i chi am ystyried cymryd rhan yn y prosiect hwn.

Rhaid imi egluro'r prosiect i chi cyn ichi gytuno i gymryd rhan.

Os oes gennych unrhyw gwestiynau: gofynnwch i mi / Ceryl Davies
(Ymchwilydd, Prifysgol Bangor) cyn i chi benderfynu a ddylech gymryd rhan.



☎ 07887888991 or ✉ ceryl.davies@bangor.ac.uk

Os ydych chi'n hapus, ticiwch bob blwch isod.	✓
Rwyf wedi darllen y daflen wybodaeth ar gyfer y gwerthusiad hwn.	
Rwyf wedi cael cyfle i ofyn cwestiynau.	
Rwy'n deall y gallaf benderfynu cymryd rhan yn y prosiect hwn.	
Rwy'n deall y gallaf newid fy meddwl ar ôl cytuno i gymryd rhan yn y prosiect hwn heb ddweud pam.	
Rwy'n deall y gallaf newid fy meddwl ynglŷn â chymryd rhan hyd at chwe wythnos ar ôl siarad â'r ymchwilydd am y prosiect yma.	
Rwy'n deall y bydd fy holl wybodaeth bersonol yn cael ei chadw'n gyfrinachol. Yr ymchwilydd yn unig fydd yn edrych dros y wybodaeth yma.	
Dwi'n deall ni fydd dim o fy ngwybodaeth bersonol yn adroddiad y prosiect yma.	
Rwy'n cytuno i gymryd rhan mewn grwp ffocws/cyfweliad ymchwil sy'n para dim mwy nag 1 awr. Rwy'n cytuno i'r grwp ffocws/cyfweliad gael ei recordio o ran y sain.	

Enw'r unigolyn/cyfranogwr

Dyddiad

Llofnod

Appendix 4: Indicative Topic Guide

I'm conducting an evaluation of Dementia Actif, Gwynedd Council. The aim is to explore people's views and experiences of the work of this Team. If you're happy to talk about this with me, I need to ask whether you agree to taking part in a recorded interview. If your happy for me to ask you whether you agree to the interview, I will start audio-recording.

- Take a break whenever you want. You can skip questions you don't want to answer. Please let me know if you don't understand a question (Read aloud consent to interview sheet).
- Reaffirm consent procedure and consent to tape record interview.
- Reaffirm right to stop the interview at any time and withdraw from the research.
- Reaffirm the confidential nature of the research interview.
- The interview guide is divided into a series of themes to discuss with participants.

Background

- Job description / role, link/working relationship with Dementia Actif.

Vision of Dementia Actif

- What do you think is the vision for older people in Wales?
- What do you think is the vision of social care for older people in Gwynedd?
- What do you think is the vision of Dementia Actif?

Interventions/Activities

- What are the interventions/activities offered by Dementia Actif?
- Explore experiences and views of interventions/activities (timely intervention, suitable staffing, convenience of location of sessions, frequency of sessions).
- What do you think Dementia Actif offers to citizens in Gwynedd?

Outcomes & Impact

- Change to individual well-being and QA life? Measuring change: e.g. ability, knowledge, attitude, understanding, keeping fit, resilience
- To what extent has Dementia Actif caused this change?
- General views on Dementia Actif?
- Being involved and asking your views.
- Ideas around measuring impact.

Ways Forward and Future Development

- Views on how Dementia Actif can be developed in the future.
- Can you tell me any strengths?
- Can you tell me any weaknesses – areas that could be strengthened?
- Any key challenges?
- Do you have any future recommendations?
- If you had a magic wand- what would you influence re support for PLWD in Gwynedd?

Explore additional issues

Are there any issues or ideas that you would like to raise that we haven't discussed so far?

Appendix 5: Case Studies

Case Study 1

Dementia Actif Gwynedd	<ul style="list-style-type: none"> Physical and social activities to support people affected by dementia
Project's Aims:	<ul style="list-style-type: none"> Dementia friendly physical activity opportunities in the community/ virtually during COVID 19 Supporting people at home by staying in regular contact and providing companion calls. Connecting people and reducing loneliness & isolation through participation in physical activity and events / online. Supporting care homes to empower residents to move more. Cultivating awareness and breaking down barriers around dementia.
Project Outcomes:	<p>Supporting people affected by dementia by improving :-</p> <ul style="list-style-type: none"> physical function health and wellbeing support network social connections dementia friendly awareness digital inclusion <p>For a better quality of life.</p>
About the person:	<p>Gentleman (75yrs) living with Dementia and his wife and only carer (73yrs) They have no family and rely on a neighbour to pick up any items they may need. They live in a very rural area of Gwynedd.</p>
What was the situation:	<p>The couple have been self-isolating since February 2020. The wife is the sole carer and is not willing to seek professional help and is anxious that if she told someone how challenging it is caring for her husband, they may 'take him away' During the past 12 months, the gentleman's dementia symptoms have deteriorated and he has lost his ability for speech completely. This has been hard for his wife as she is no longer able to have a two-way conversation, which is extremely frustrating for both of them. One of Dementia Actif Gwynedd's main priorities during the pandemic has been to keep in contact with participants and support people to get online to join online activities. However, the couple don't have access to the internet by choice and have no interest in joining online activities. The main aim in helping this couple is to ensure that they have some connection with others, feel supported and less isolated. Also that they have the means for additional support from local authority Social Services should the need arise.</p>

Impact statement	<p>Dementia Actif Gwynedd staff have endeavoured to support the couple in their preferred method of contact, which has been regular phone calls. The wife reports that the weekly phone calls have been a lifeline and have been sufficient support. The calls gives her an opportunity to speak to someone as she is no longer able to have a conversation with her husband. Although the couple do not join Dementia Actif Gwynedd's online activities such as the Keep Agile exercise class, virtual Coffee Morning, Sporting Memories Clubs etc. the staff have been determined to keep the couple engaged and included throughout:-</p> <p>Example</p> <p>Ensuring that they receive hard copies of the monthly newsletter. The newsletter keeps them up to date with news and events, as well as with useful information such as phone numbers of important services that could support them</p> <p>The newsletter also includes exercises that the couple can do at home without having to join an online class and there is a photo gallery so the couple can see what other DementiaGo participants have been doing which they say makes them feel connected.</p> <p>Recently the wife joined Gwynedd Council's Intergenerational Pen Pal scheme with the help of the staff. She receives letters and cards from a local Primary School and she enjoys replying to them. She feel that this helps her feel less isolated and gives her something else to look forward to.</p>
Outcomes achieved	<ul style="list-style-type: none"> • Sense of connecting with others • Sense of belonging • Sense of inclusion • Less depressed • Sense of support • Less isolated • Increased motivation • Increased physical activity
Quote	<p>•<i>"You make us feel a part of everything all the time, we don't feel missed out on anything or shut off"</i></p> <p>•<i>"You help and support me which helps me look after my husband"</i></p> <p>•<i>"I sometimes get depressed when thinking 'why him, as soon as I speak to you I know we have a laugh and I'm not depressed anymore. You're always on the other side of the phone. By the time I put the phone down, I feel much better and tell my husband everything we spoke about and this makes him smile and laugh too."</i></p> <p>•<i>"When he can't talk it makes me feel so down and isolated but I don't feel isolated when I talk to the DementiaGo family...I do all the talking and I know I don't stop but it's because I don't talk during the day"</i></p>

- "You're not going to believe this but sometimes I get all the newsletter out and put them on the floor and we choose which exercises to do. We do them every other day. The newsletters are a god-send, full of useful information, exercises, recipes ideas... I read it all to Mike but I don't let him do the word search!"*
- "He shakes his hands, waves his arms and smiles when sees a photo of you or your work colleague in the newsletter...it helps him remember. It shows me he can communicate too without having to use words or talk"*
- "The pen pal letters really cheers you up. It's like the newsletter, it comes through the post and makes you smile. It's nice to read what they have to say and I didn't think that I would write back to begin with but I did, and I can't wait to write back to the new one I have received"*
- "You don't have to worry that you're not going to talk to anyone, I know you will call and we have a laugh. My husband sees me laughing and this makes him laugh too. Having a laugh when with Dementia is a big thing"*
- "If we hadn't have had DementiaGo I don't know what would have happened, we would have been so isolated. We are frightened but DementiaGo helps you not feel frightened, you help us know what's going on"*
- "We don't do the internet and so can't find things out easily, but you can always find the information for us"*

Appendix 5: Case Study 2

Dementia Actif Gwynedd	<ul style="list-style-type: none"> Physical and social activities to support people affected by dementia
Project's Aims:	<ul style="list-style-type: none"> Dementia friendly physical activity opportunities in the community/ virtually Supporting people at home by staying in regular contact and providing companion calls. Connecting people and reducing loneliness & isolation through participation in physical activity and events / online. Cultivating awareness and breaking down barriers around dementia.
Project Outcomes:	<p>Supporting people affected by dementia by improving :-</p> <ul style="list-style-type: none"> physical function health and wellbeing support network social connections dementia friendly awareness digital inclusion <p>For a better quality of life.</p>
About the person:	<p>A man living with dementia and his daughter, who is also his main carer during the week. The man living with dementia is referred to as the 'father' in this Case Study</p>
What was the situation:	<p>During the COVID 19 pandemic, the father and his daughter had been isolating in the family house. The daughter stays to care for her father during the week and goes back home during the weekend whilst another family member takes on the caring role. Over the months, father had become 'housebound' and lacked the confidence to go out at all. The daughter was very aware of how this was affecting his health and wellbeing and was eager to address the situation so that he could start connect and communicating with other people.</p> <p>The daughter had started attending an online Dementia Carers group run by the Dementia Actif team, which she has seen advertised in a local shop. During one of the sessions, she heard about Dementia Actif's latest programme of activities and became interested in the Gardening Club, which was local to them. The father and the daughter attended the first session at the garden in April and became regular participants enjoying the activities and the socialising.</p>

Impact	<p>The father gained more confidence to go out and take part in the activities. He thoroughly enjoys the activities in the moment, although he may not remember where he has been once he arrives home. The social interaction has been beneficial and he has started to get to know the other participants, in particular the Dementia Actif Instructors.</p> <p>The effect that the gardening activities has on the father has a positive impact on the daughter. She is a keen gardener and gets very involved with the activities. She also enjoys being able to share doing the activity with her father. One of the main benefits she feels is being able to have some social interaction with others in the group, as she spends the week caring for her father she doesn't get the time to herself to socialise with others.</p> <p>The daughter reported feeling supported by the Dementia Actif team, through the Carers Support Group and the Gardening Activities, especially as she gets to meet other carers who understand what's she's going through as a carer for her father.</p> <p>She also really appreciated the information and advice she has received from the Dementia Actif team and other group participants.</p>
Outcomes achieved	<ul style="list-style-type: none"> • Sense of connecting with others • Sense of belonging • Sense of inclusion • Sense of support • Less isolated • Increased social interaction • Increased motivation • Increased physical activity
Quote	<p><i>For the hour my Dad is in the gardening session he is good, but once we're home after the session he forgets. I think it makes more of a difference and benefits me more than him. I get to talk to other carers and learn from others, such as today, another carer shared information about Carer's Outreach that I wasn't aware of. When I'm in the gardening session, although I've got Dad with me, it's nice to have a break when someone else is with him.</i></p> <p><i>'In a lot of ways, although this is more useful to me than it is to him. It's still quite new to him. The more he will come the more it will become a routine and he will remember'.</i></p>