Dementia Friendly Swimming

Making swimming accessible for people with dementia:

The Swim England Dementia Friendly Swimming Project

Final Report December 2017

Swim England

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Executive Summary

Swim England's Dementia Friendly Swimming (DFS) project was one of 30 voluntary sector projects to be awarded a grant in 2014 by the Department of Health's Innovation, Excellence and Strategic Development Fund.

Its overall aim was to stimulate greater use of swimming pools by people with dementia (PwD) and their carers through a transformation in culture and practice that makes swimming services and the swimming environment more appealing, fit for purpose and customer centric.

The project included the following components:

- Appraisal of the facility itself and environmental changes to make sure it was conducive for people with dementia.
- Training for staff to improve their understanding of dementia and how to provide support.
- Development of partnerships to drive recruitment.
- Development of persuasive information describing the benefits of Dementia Friendly Swimming to people with dementia and their carers in motivating language.
- Creation of supportive, enjoyable and safe swimming and aquatic exercise experiences.

From the start, flexibility was built into the guidance and resources so that newly adopting schemes had the freedom to tailor their offer to best serve local needs and conditions.

A multi-method, action-research approach was designed and implemented. Because of the absence of directives from previous research, Swim England sought to maximise learning as the project progressed, and to feed this learning into subsequent stages of development. Regular collection of qualitative and quantitative data throughout each stage meant that it was possible to build up comprehensive guidance and a support system for existing and new DFS schemes as the project progressed.

A series of resources were designed and created to support the development of the project and placed on the website. Since the project began the website has been visited by 7,814 unique users with a total of 9,879 visits and 25,969 page views.

Environmental changes

Swim England, with the support of the Dementia Design Consultancy, produced a guide and an assessment tool for appraising the dementia friendliness of a leisure centre entitled: *Is your leisure centre dementia friendly: An environmental analysis and change tool*. 102 leisure centres have used the checklist and many operators see that further improvements are possible and that appraisal should be a continuous process. Pools have commented that the changes made have also benefited people with other conditions such as visual impairment, mobility and balance problems, learning disabilities, autism, and people whose first language may not be English.

Training outcomes

- 895 leisure staff have received *understanding dementia training*, with all trainees registered as Dementia Friends. In addition. Dementia Friends training was also offered through the project partners to staff in Libraries, Age UK and councils. It was also delivered to local

Councillors so that they felt more equipped to support people living with dementia in their local communities. This created an additional 286 Dementia Friends.

- 64 people have been qualified as cascade deliverers for *Understanding Dementia in a Leisure Environment* training, and are continuing to train their peers. This means the reach of the training is likely to be greater over time.
- An evaluation of training showed that almost all attendees on the course increased knowledge and understanding of dementia and confidence to know how to support a person with dementia.
- Almost all course attendees (98 per cent) increased knowledge and understanding of dementia and confidence to know how to support a person with dementia.
- 64 per cent felt that the provision for vulnerable people and those with health problems had improved, and also that outreach through partnership working had increased.
- 54 per cent felt they have changed the way they communicate.
- 27 per cent have become a dementia champion and acting as advocates for people with dementia.
- 64 per cent felt that practice at their centre has become more inclusive.

Development of partnerships

Operators delivering DFS have developed partnerships with a diverse range of public and private organisations and charitable trusts including:

- Local branches of Alzheimer's Society
- Age UK
- Young Onset Dementia Services
- Housing providers
- Adult and Social Care Services
- Council officials
- Community health nurses
- Local care providers and carer organisations

DFS schemes are included in at least eight Dementia Action Alliances (DAA) across the country and Swim England continues to encourage more leisure partners to join their local DAA and commit to working towards becoming Dementia Friendly. In some areas, partnerships with transport providers to help overcome barriers to attendance have also been successfully developed.

These stronger links with health and social services has built understanding and helped bring leisure services into focus for other ventures that require close working with care commissioning groups and populations such as older adults, or people with obesity, diabetes, mental health challenges.

Marketing materials

Swim England undertook research to provide ideas and strategies for increasing recruitment of PwD to the DFS programme. This work, along with the collection of learning from the projects, has allowed Swim England to learn and evolve strategic guidance for new schemes in their attempts to establish PwD groups.

A number of recruitment strategies have been identified as beneficial and implemented. These include:

- In-person visits to established groups where PwD meet such as care homes, social events, assisted housing, Memory Cafes, community centres and activity sessions.

- Preparation of specialist publicity materials that can be left for PwD to spend more time reading and that address specific concerns, needs and potential barriers.
- Provision of visual aids where possible such as videos of the journey through the leisure centre and of the sessions.
- Setting up taster and walk through sessions for groups and providing transport.
- Facilitating word-of-mouth recommendations through use of testimony, case descriptions, and short presentations/videos.

Creation of aquatic opportunities

A number of types of opportunity have been developed:

- Provision of protected space for swimming laps in the main pool. The advantages of this approach is that it causes minor disruption to other swimmers and is also relatively cost effective to deliver.
- Provision of an aquatics session that is dedicated to PwD and their carers. It is usually more varied involving aquaerobics, relaxation activities (Aqua Relax), water-based games and use of swimming aids.
- Beach parties where an emphasis has been placed on recreating and recalling positive memories of the water and swimming (such as recall of holiday experiences). Pool parties have been offered as a format to attract people to their first session.
- Mixed condition/inclusion sessions which cater for people with a range of long term conditions. These sessions are perceived by operators to be a more sustainable and cost effective solution.

In addition, the project has found that social interaction is important for PwD and their carers. Availability of a social space or a café following activity is proving to add value and social time has been tagged to the activity session creating a more holistic approach where mental well-being, enjoyment, and social interaction have taken priority.

Reach of the scheme

By the end of the funding period of the programme:

- 48 leisure operators/pool providers had engaged with the project delivering opportunities in 102 pools.
- It is estimated that that the project reached a minimum of 1,276 people with dementia. This consists of:
    - 212 who have registered with Dementia Friendly Swimming schemes.
    - 319 who have not registered but are attending dementia-only sessions.
    - 745 people with mixed conditions who attend dementia-only sessions.

  This is considered a conservative estimate of the full impact of the scheme.
- It is estimated that the project has reached 335 carers.
- Schemes in Year 1 and Year 2 reached between 1.6 per cent and 2 per cent of the diagnosed population, but with the exponential growth recruitment it is believed that it is possible to reach 3-4 per cent in the future.

Profile of participants

From the data collected the following in known about the participants:

- There was an even split of men (53 per cent) and women (47 per cent) with dementia.
- Carers were predominantly female (86 per cent).
- 80 per cent of people with dementia were over 65, while 50 per cent of carers were over 50.
- An average of 37 per cent were living independently either alone or with someone, but this varied greatly depending on the area.
- Most people had been diagnosed between one and three years ago (48 per cent).
- 57 per cent classed themselves as having a disability.
- 53 per cent finished their education after secondary school.
- 35 per cent of people with dementia had been active less than two times in the previous month before staring the scheme.
- 36 per cent of people with dementia could not swim or required aids to swim.
- The top reasons for people with dementia attending the sessions were:
    - "Enjoyment of swimming"
    - "The potential of meeting new friends"
    - "The opportunity to get out of the house and to get fit and healthy and to stay active and mobile"
- Top reasons for carers attending sessions were:
    - "To bring the person I care for"
    - "To do activities with the person I care for"
    - "An opportunity to meet new friends and enjoy swimming"

Maintaining attendance and reducing absences

The following factors have been identified as supporting attendance at the sessions and reducing absences:

- Empathetic and skilful staff.
- An induction that puts people at ease and addresses their concerns.
- Improved pool session timetabling and making the environment more appealing.
- Providing opportunities for social interaction.
- Keeping feedback channels open.
- Taking measures to address drop out of participants.

Key outcomes

A small number of participants were followed up (PwD n=34 and Carers n=14) at six months:

- 69 per cent of participants indicated they had become more active as a result of participating in the programme.
- 53 per cent of people with dementia felt their water confidence had higher increased.

Interviews with participants held at the end of the funding period also highlighted the following:

- Improvements in physical well-being including pain reduction, balance, functional capacity and fitness.
- Improvements in psychological and social well-being including improvements in mental health, the opportunity to socialise, improved mood, gains in general confidence, confidence in cognitive and physical abilities, feeling more alert and mentally stimulated, increased ability to concentrate and reduction in anxiety.

- Some indication of improvements in water confidence with the proportion of participants rating their water confidence as *high* showing an increase from 31 per cent to 53 per cent, and levels of *high confidence* amongst carers showing an increase from 59 per cent to 92 per cent.
- Some indication of improvements in swimming ability (approximately 50 per cent of people with dementia and their carers who responded).
- Benefits to carers included ability to socialise with other carers and share experiences, a springboard for other social opportunities, and enabling an enjoyable activity for their people with dementia.

Health economics

A desk-top study was conducted using the Model for Estimating the Outcomes and Values in the Economics of Sport (MOVES v2). The model predicted average NHS savings of £51 per participant and a small QALY gain, primarily through the prevention of hip fracture. Prevention of coronary heart disease was also an important contributor to the predicted benefit. This compared to an average operating cost of £36 per participant. The return on investment to the NHS was estimated to be £1.42 per £1 invested, or 42 per cent . If one assumes that carers participated at the same intensity and duration as persons with dementia, and derived the same protective benefits from swimming, the return on investment increases to £2.19 per £1 invested, or 119 per cent .

Benefits to leisure services

- Bringing new types of customers with different needs has widened perspectives of staff, made them more aware of dementia and improved service.
- Changes in signage, route way markings, and more careful consideration of social areas have been beneficial for all customers but particularly those with health needs.
- Some centres have been alerted to their importance as a social venue and as such have developed new policies to upgrade their catering and increase use of their social spaces.
- Dementia Friendly Swimming sessions help leisure services fulfil their duties to community welfare, which for leisure trusts is a clear part of their charter.
- Senior managers were impressed with the programmes and supportive despite challenges and extra work involved to make Dementia Friendly Swimming successful.
- Increased awareness of the need for and expertise in outreach has resulted in the development of rewarding partnerships with other organisations, created a better understanding of community needs, and opened up other possibilities.
- Insight from Dementia Friendly Swimming can be used to inform future commissioning priorities and carry learning into future projects.
- In some cases, Dementia Friendly Swimming has helped leisure services raise their profile within Public Health and Social Care.

Benefits to partners

- New and stronger partnerships have been forged as a result of the programme, for example with local Dementia service providers.
- The programme has already brought, and is likely to increase, the investment and resources available to run Dementia Friendly Programmes in some local areas.
- Partners believe that Dementia Friendly Swimming will increase the likelihood of physical activity interventions being commissioned by health bodies in the future.
- Increasing the profile and strategic importance of dementia locally.

- Provided a new element of implementation of local Dementia Strategy.
- Created a new work force of Dementia Friendly trained staff.
- The project has contributed to removing the stigma and barriers associated with dementia in the local community.
- Improved information sharing and collaborative working between organisations.

The future

Swim England will seek to disseminate the findings of the evaluation alongside all the tools developed to support the project, through promotion of the website, giving presentations at relevant conferences and delivering a seminar to share the findings.

Swim England is seeking to build upon the work undertaken to expand the programme to incorporate people with mixed health conditions. Swim England is seeking to create cost effective solutions that will maximise the use of the pool and deliver aquatic opportunities to target the least active and improve their health and wellbeing.

Swim England will work with the some of the existing Dementia Friendly Pools to develop the model and ensure it is feasible and sustainable. With a potential reach of over 2,780 public pools this could make a significant and lasting contribution to the health of the nation by reducing inactivity and supporting people with long term conditions.

Introduction

Swim England (formerly the Amateur Swimming Association) is the English national governing body for swimming, diving, water polo, synchronised swimming and disability swimming. Swimming is currently the most popular participation sport in England.

Swim England's vision is a nation swimming and its mission is to create a happier, healthier and more successful nation through swimming. Swim England is committed to supporting the delivery of the Government's Sport Strategy *Sporting Future - A New Strategy for an Active Nation* (DCMS 2015) and delivery of the Public Health England *Outcomes Framework* (PHE 2017).

Each year thousands of children and adults learn how to swim through the Swim England Learn to Swim Programme. It also supports over 1,063 affiliated swimming clubs and works closely with leisure and community services to promote swimming and aquatics for all.

Figure 1: Swim England's Swimming and Health Commission Report, 2017

In 2017 Swim England commissioned an independent expert review of the evidence base for the health and social benefits of swimming. The review (*The Health and Wellbeing Benefits of Swimming*, June 2017) summarised the substantial physical and psychological effects of regular swimming. These included reduced risk of early disease, and improvement in well-being and functional fitness. Of particular significance is that these benefits can be experienced by people throughout their lifespan. Swim England encourages everyone to take advantage of all these benefits through regular aquatic activity, regardless of age, gender, faith, ethnic origin, sexual orientation, economic position, current state of health, disability or level of ability.

There are 850,000 people with dementia (PwD) in the UK at an estimated cost of £18 billion per year. About 225,000 people will develop dementia this year and now one in six people over the age of 80 has dementia. Numbers are projected to rise to over one million by 2025 and two million by 2051, with exponential rises in health and social care costs (Alzheimer's Society, 2018).

Swim England's Dementia Friendly Swimming (DFS) project was one of 30 voluntary sector projects to be awarded a grant in 2014 by the Department of Health's Innovation, Excellence and Strategic

Development Fund. Its overall aim has been to stimulate greater use of swimming pools by PwD and their carers through a transformation in culture and practice that makes swimming services and the swimming environment more appealing, fit for purpose and customer centric.

This final DFS report outlines progress to the end of October 2017. However work continues, as Swim England has pledged to facilitate continued uptake of DFS by sharing learning and spread the scheme to more regions and localities. In addition, Swim England will apply learning from DFS to the improvement of aquatic provision for people with other health conditions and disabilities such as muscular skeletal conditions and mental illness.

1. Project approach

The project approach was developed through collaboration with relevant national agencies including the Alzheimer's Society, and has become a feature of the Prime Minister's Dementia Challenge of producing four million Dementia Friends by 2020. The focus has been on achieving sustainable and comprehensive changes in practice that are necessary to support year-on-year increases in the numbers of PwD and their carers who regularly using swimming facilities.

For aquatic provision for PwD and their carers to be effective, Swim England recognised that a substantial reappraisal and upgrade in current practice in swimming and leisure facilities was required. The Department of Health funding for DFS has been critical to the development of a blueprint for action to enable leisure operators to transform their current provision so that it is an attractive and supportive option for PwD and their carers. Modifications to facilities, education and upskilling of staff, the development of a range of models of service delivery that maximise appeal for PwD and their carers, and a bank of supportive resources for health and leisure professionals were needed if swimming pools were to become truly dementia friendly and effective in attracting and retaining new beneficiaries.

The need for a developmental strategy to upgrade aquatic services to become more person-centred for PwD was reflected in the original proposal for funding. A three-year staged approach to allow progressive learning was set out and has been used to formulate, operationalise, and assess the feasibility and acceptability of models of service delivery.

When DFS was proposed, little was known about how best to tailor the aquatics experience for PwD and their carers, or indeed physical activity promotion in general for this population. There were no off-the-shelf training and support packages available to support practitioners in the field and so it was essential to maximise learning and build it into practice as we progressed. Therefore, the project started with two pilot areas in Year 1 (November 2015) where learning through extensive appraisal and feedback provided the focus. A further five partners were added in year two to provide further refinement and to observe how delivery was modified in diverse settings. By the end of Year 2, standardised resources and support materials were made available for use in year three and beyond.

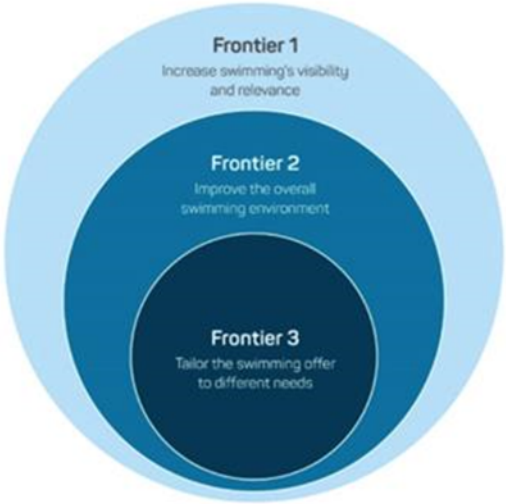
From the start, flexibility has been built into the guidance and resources so that newly adopting pools have the freedom to tailor their offer to best serve local needs and conditions.

Key strategies built into the project have included:

- The **creation and roll out of dementia friendly training** for all leisure centre and pool staff.
- **Development of partnerships** with local authorities and charitable organisations such as Alzheimer's Society to help train staff about the needs of people with dementia and how to attract them to dementia friendly swimming services.

- A tried and tested **checklist with accompanying guidelines for enhancement of facilities and services** to increase accessibility and dementia friendliness on site.
- **Strategies and resources to support project delivery** including shared branding, regular group and face-to-face meetings, online case descriptions and *lessons learned* documentation that encourage sharing of learning.
- **Provision of tailored water-based exercise sessions** including aqua-fun sessions, relaxation sessions and structured motivational swimming lessons for people with dementia and their carers.
- **Modification of existing pool sessions** to make them more inclusive.
- **Standardised monitoring and evaluation of participant numbers** across all pilot pools to enable ongoing analysis of demographics of recruitees and their attendance.

Figure 2:
Swim England's Three Frontiers Strategic Model



The strategies listed above encapsulate Swim England's Three Frontiers Strategic Model for growth in swimming, which is based on behaviour change research and illustrated in Figure 2. This model shows the need for a whole-pool approach to supporting the customer journey including: appropriate marketing to highlight the relevance and value of swimming, an inclusive environment, knowledgeable and empathetic staff and tailored provision to meet the needs of specific populations. DFS is entirely consistent with this approach to supporting customers to develop a consistent swimming habit and become advocates of regular swimming.

The DFS project has been an innovative example of a top-down public health intervention. It is initiated, coordinated and facilitated by a national organisation - Swim England - using a consistent support and evaluation methodology but is delivered with flexibility at the local level to reflect local conditions and needs. Swim England delivered a support structure for local authorities and leisure operators to modify their swimming provision to support customers' needs. In the process there is overwhelming evidence from an extensive monitoring and evaluation package that DFS has brought considerable benefits for PwD and their carers, and at the same time improved swimming pool and leisure centre services so that all users can benefit from enhanced customer experiences.

2. Research approach

Following allocation of funding, the evaluation and monitoring plan was further developed and implemented in partnership with Professor Ken Fox of the University of Bristol who has expertise in physical activity interventions and effects of exercise on mental health. Grace Clancey and her team at Continuum Sport and Leisure Ltd have worked with Sport England and Sporta and were commissioned to lead data collection. The University of East Anglia Health Economics Department under the leadership of Dr Chris Skedgel was asked to conduct a separate health economics analysis of DFS. In the design of the evaluation we were mindful of the conclusions of the most recent review of the existing research literature on physical activity for people with dementia:

> *Despite potential benefits demonstrated in literature and practice, there is a need for further research to optimise interventions and to consider some neglected issues including delivery at home and in communities; impacts for carers; physical activities through ADLs; and individual needs. Studies are needed which take a more holistic approach to the effects of physical activity, and outcomes should be broader and include mental health and wellbeing. There is a general lack of clarity regarding how physical activity interventions work, what outcomes can be expected, and what outcomes are sought.* [**Source: Bowes et al. BMC Geriatrics 2013, 13:129]**

As a result, a multi-method action-research approach was designed and implemented. Because of the absence of directives from previous research Swim England sought to maximise learning as the project progressed, and to feed this learning into subsequent stages of development. Regular collection of qualitative and quantitative data throughout each stage has meant that Swim England has been able to build up comprehensive guidance and a support system for existing and new DFS pools as the project progressed. Monthly tracker data was centrally held and provided a constantly updated picture of the adoption and usage of DFS services and also advised Swim England the profile of participants. This approach is in contrast to the standard randomised controlled trial design (not feasible with DFS) where intervention delivery is standardised, non-modifiable and results are not available until well after project completion.

A DFS logic model guided project design, and determined key outputs and measures of impact (see Figure 3). A comprehensive portfolio of data collection tools were developed and applied in all DFS areas, pools or projects. Several packages of data collection were conducted, with several being small research projects in their own right.

Data collection methods used

Principal data collection methods included:

- A standardised continuous audit of participant recruitment and retention at each pool through a centralised tracker system (number of contributing areas to date n=34 but continues to grow).
- Baseline participant and carer questionnaires to provide data on individuals' demographics, diagnosis, means of recruitment, expectations, preferences, swimming experience and confidence, physical activity and psychological well-being at sign up (Year 1 and 2 sites, n=185, including Year 3 sites n=583).
- Repeated participant and carers questionnaires assessing confidence, ability, motives, barriers, physical activity and general health (n=52).
- Interim (end of Year 1) telephone interviews with scheme coordinators indicating nature of provision, staffing and funding issues (n=2).
- Detailed scheme reports provided by scheme coordinators (n=11) (ranging from 4 to 30 pages) illustrating models of delivery, recruitment and marketing methods, monitoring, and lessons learned.
- A Year 2 unintended consequences survey of DFS leisure and non-leisure service partners (n=31) that identified the benefits and challenges of the scheme to partners.
- Questionnaires (n=241) and web-based survey (n=59) conducted by Swim England to assess the impact of Dementia Friendly Training on staff knowledge, confidence and practice.
- Telephone interviews (n=40) with providers of care services to determine the challenges and facilitators involved in getting their clients involved into DFS.
- End of project face-to-face interviews with participants (n=15) and their carers (n=11) to assess personal challenges and benefits.
- End of project face-to-face interviews with leisure providers offering DFS (n=22)
- Sharing of experiences at six monthly coordinator meetings (6 in total) and incorporating informal feedback provided by participants and carers.
- End of project unintended consequences survey of DFS partners.

Figure 3: Dementia Friendly Swimming Logic Model

Context/rationale	**Inputs/activities**	**Outputs**	**Outcomes** *(short to medium term within the project time)*	**Impact** *(longer term some will sit beyond project time)*
Key issues/problems that you are trying to address through the programme/service and why this type of programme/ activity is needed: • 850,000 people living with dementia in the UK • 610,000 people living with dementia in England • Currently costs UK Economy £26 billion a year. • In the next 30 years, the number of people living with dementia is expected to double to 1.4 million at a cost of over £50 billion • Swimming is a great all-round activity that is particularly beneficial for people living with dementia as the sensation of being in the water can provide a calming and soothing effect. It offers a sense of mental wellbeing and relaxes and supports the body in a relatively weightless environment which reduces anxiety.	**The activities you are delivering through the programme/service:** Deliver a dementia friendly swimming project with the following components: • Recruitment of delivery partners and co-ordinators. • Development of local working groups with non-traditional partners. • Development and delivery of understanding dementia in leisure environments training for leisure centre/pool staff. • Signing people up to the Government's Dementia Friends public health campaign. • Development of assessment tool giving guidance on environmental modifications. • Development of planning and marketing resources. • Pool operators undertaking facility	**The direct outputs from the programme/service – usually things that can be quantified and collected through monitoring data:** • Number of pools. • Number of co-ordinators. • Number of working groups and membership. • Number of courses delivered. • Number of people trained. • Number of cascade trainers. • Number of hits on website. • Number of assessments undertaken/action plans developed. • Number of organisations linked with. • Number of participants, people with dementia/ carers – gender, age bracket, ethnicity. • Number of classes/ sessions. • Number of carers engaged.	**The outcomes you would expect to see during the lifetime of the programme/service:** • Pool operators have made environmental improvements. • Recruitment pathways/ routes established with key organisations that support people with dementia. • Training sessions have been delivered. • Cascade trainers have been trained. • Staff trained and actively using their learning in their daily role. • Carers have participated in the programme. • People living with dementia participated in the programme. • People living with dementia and carers still attending at three and six months and one year. • Participants and carers see improvements in health	**Longer term impact resulting from the outcomes:** • People affected by dementia (people living with and their carers) have improved health and well-being. • All swimming pools are dementia friendly and actively recruit member with dementia and their carers. • Other activities influenced within the leisure environment to become dementia friendly (not restricted to pool activities), creating dementia friendly leisure centres. • Cost savings to national and local economy. • Swimming seen as an attractive opportunity for people with dementia. • Other sports and partners go on to apply learning from swimming project.

• Swimming sessions can also help to reduce loneliness by creating opportunities to socialise and make new friends. • People living with dementia face a number of barriers in accessing swimming and other aquatic activities these include the pool environment and concerns that instructors and wider pool staff will not understand their needs. • Aim to change perceptions by removing barriers and ensuring that swimming pools are as safe and welcoming as possible to help encourage more people to enjoy the benefits of swimming. • By improving the health and wellbeing outcomes for people with dementia we hope to support cost savings to society.	assessment to make environmental changes. • Pool operators undertake consultation with user groups. • Recruitment of people with dementia and their carers by local coordinators. • Dementia friendly specific sessions and classes to be set up (integrated or exclusive). • Action-based research at each stage through lessons learned reports.		and well-being and swimming ability. • Sustainability plan developed for post 2017. • Benefits to pool operators who want to continue to be engaged. • Alzheimer's UK engaged and want to continue with the project.	

3. Data collection and analyses

DFS scheme coordinators have been required to collect and report back information on the participants and carers who have registered with the programme. Years 1 and 2 of the programme were set up to provide learning to guide further developments and received dedicated funding for DFS coordinator posts. These posts assumed responsibility for collating the monitoring and evaluation data from participants and carers in their scheme and were fed into a centralised tracker. Year 3 schemes were not given funding for a DFS coordinator and, while they were given access to the full monitoring and evaluation instruments used in Years 1 and 2, they were only required to collect a headline data set on participants and carers.

Additional elements of the research, such as surveys and interviews, were independently conducted by Continuum who have a research team with experience in the leisure/sport context. The DFS research team regularly extracted registration, follow-up and interim data to gain insight into the characteristics of programme beneficiaries and map changes over time. Analyses and results have been presented at four and six monthly coordinator meetings and have furnished development of support materials for the web-based DFS Toolkit.

Figure 4: Project Time Line

	Oct-14	Oct-15	Oct-16	Oct-17
Durham	Coordinator Funded			
Manchester	Coordinator Funded			
Nottingham		Coordinator Funded		
Bristol		Coordinator Funded		
Crawley		Coordinator Funded		
Barking & Dagenham		Coordinator Funded		
GLL (Tower Hamlets & Hackney)		Coordinator Funded		
Year 3 areas/sites			No Coordinator Funding	

Data collection proved to be challenging, in particular for areas that did not have funded DFS co-ordinators and could only provide limited support to PwD and their carers to complete forms. PwD often have reduced cognitive capacity, difficulties with recall, and shorter attentions spans. Questions were asked verbally by DFS coordinators which was more time consuming. Although carers often helped PwD with answers, not all were family members and these carers had more limited knowledge of their clients. Data collection in some schemes was more successful, because of greater time allocation and perseverance.

A second challenge proved to be the ability to capture participation data for people attending mixed condition sessions or attending open swimming sessions. Some of the current leisure centre systems do not track information on who attends each session when they pay at the till. For those who do have membership systems in place that allow individual's attendance to be tracked, they do not currently collect information about the specific health status of the individual. The overall data set therefore is not considered to be fully representative of the total number of people who have benefitted from the programme.

The pre-post comparison group health economics assessment of effect of the programme on the quality of life of participants and their carers was initiated by the University of East Anglia. Unfortunately, considerable delay resulted from the NHS ethics approval process. PwD are considered a vulnerable group and questions were raised about judging the capacity of PwD

entering the programme to provide meaningful consent to join this section of DFS research. As concerns were already being expressed by DFS scheme coordinators of the existing burden on participants, a joint decision was made early in 2017 by Swim England and the University of East Anglia to terminate the health economic analysis in favour of a desk top study to estimate the health impact of change on physical activity of participants.

Swim England also supported two medical student dissertations conducted at the University of Nottingham. These projects assessed barriers and facilitators to participation in DFS through seven session observations and 14 interviews with PwD and/or carers in the Nottingham DFS scheme. Copies of the final reports will be available on the Swim England's website from February 2018.

This report summarises and combines all available quantitative and qualitative data to the end of October 2017 to provide insight on the key learning outcomes and impacts of the project. Emphasis is placed on quantitative data and reports from Year 1 and 2 schemes as these are well-established and provide a larger number of reliable responses. However, end of project interviews have provided rich insights into DFS and how it has been received by participants, operators and partners.

Section A: Creating a Culture for Change

Following the Three Frontiers Model (see Figure 2), Swim England realised it was crucial that DFS project was designed to be appealing and sensitive to the needs of PwD, and also that the setting was easy to navigate and provided a non-threatening, safe, welcoming, and comfortable opportunities. This information needed to reach PwD and their carers in a way that motivated them to take part. This meant a four pronged approach that included:

- Appraisal of the facility itself to make sure it was conducive for PwD.
- Training for staff to improve their understanding of dementia and how to provide support.
- Creating and supporting enjoyable and safe swimming and aqua-exercise experiences.
- Finding ways of delivering persuasive information describing the benefits of DFS to PwD and carers, in motivating language.

Figure 5: Steps to establishing a Dementia Friendly Swimming Programme

Engage with operator or organisation
- Swim England identifies and approaches lead contact in each area, using the DFS Toolkit to sell the benefits of being involved in the project.

Scope
- Once partner organisation is on board, Swim England works through the Three Frontiers and relevant resources in the toolkit to support areas to identify their aims and objectives in becoming dementia friendly.

Local Project Management
- Local area sets up working group and establishes sites for delivery, work programme and timescales.
- Area consults with external partners in dementia/older people services to identify structures in place for people living with dementia and their carers and pathways into the scheme.

Environment
- The sites use Dementia Friendly environment checklist to identify small improvements which could be made.
- Swim England co-ordinates with Alzheimer's UK to arrange training using the training checklist and booking form.

Set up Support
- Areas link with community partners to create a steering group, identify where support is needed in three frontiers.

Tailor the need
- Areas use toolkit case studies and advice from stakeholders to identify suitable pool time and support needed.

Environment
- Sites undertake improvements identified from checklist.

Visibility and Relevance
- Swim England shares marketing templates and guidelines with partners for them to amend and produce for their local area.
- Areas develop marketing methods and begin recruitment and launch scheme.

Monitor, Review and Support
- Swim England briefs partners on the monitoring and evaluation process for recording participants - registration forms available in toolkit.
- Swim England holds regular meetings with partners to highlight any support needed, evaluate project, share best practice and provide any feedback.
- Quarterly data returns are completed by the areas.

1. Dementia Friendly Training

The DFS project has taken full advantage of the Alzheimer's Society Step Inside Dementia Awareness training. Step Inside is a one-day equivalent programme designed to enable staff and teams to begin to understand the experiences and challenges facing people living with dementia and to help staff provide better customer service and a more helpful, supportive environment. The programme is also available as a cascade product so that it can be delivered in house to new staff.

As the project has moved forward, the training has been adapted and improved to make it more directly relevant and bespoke to the leisure centre setting. It is now called *Understanding Dementia in a Leisure Environment*. The project is therefore delivering important training to staff who have had limited exposure to people who have significant health needs.

At the end of October 2017, 895 leisure staff had received DFS training with all trainees also being registered as Dementia Friends. In addition Dementia Friends training was also offered through the project partners to staff in Libraries, Age UK and councils. It was also delivered to and local Councillors so that they felt more equipped to support people living with dementia in their local communities. This created an additional 286 Dementia Friends.

Trainees have come from most sections of leisure service delivery with receptionists, managers, coaches/trainers and lifeguards being the majority. Usually staff have volunteered to attend but have been allowed training as paid time. Sites reported that staff encouraged each other to attend so that coverage is high. The Nottingham site, for example, over 50% of staff have been trained. A total of 149 leisure staff have been trained in the Bristol scheme and 130 in the Durham scheme.

In a business that sees quite high staff turnover and many part time workers, sustainability of high quality delivery is enhanced by a total of 64 staff now qualified as cascade deliverers have been trained.

The impact of training on staff has been evaluated by Swim England through a 241 feedback questionnaires completed immediately following the course and a web-based survey (59 responses) conducted in August/September 2017, which was between six and 12 months after training. As most pools are located in leisure centres, questions referred to leisure provision in general.

Both data sources clearly established that for almost all attendees the course increased knowledge and understanding of dementia and confidence to know how to support a person with dementia. In addition the follow-up survey indicated that participants felt better equipped to cater for a person with dementia in the leisure setting. Also 54 per cent felt they have changed the way they communicate and 27 per cent have become a dementia champion. In addition, 64 per cent felt that practice at their centre has become more inclusive, 64% felt that the provision for vulnerable people and those with health problems had improved, and also that outreach through partnership working had increased.

These findings are backed up in the project reports of several schemes indicating that training was seen as "enjoyable", "enlightening" and "highly valued time" (copies of these final reports will be uploaded to the Swim England website in February 2018). The benefits are also seen through the words of participants and their carers who have consistently indicated high appreciation for staff and their responses.

Leisure Centre staff comments on Dementia Friendly Training

I feel more comfortable in realising how dementia could affect someone. I'm looking forward to taking this knowledge into the swimming pool. **(Manager)**

The special *glasses were an excellent insight into possible visual problems.* **(Sports assistant)**

I have learnt how to deal with people with dementia and it has made me really interested. **(Receptionist)**

Helpful and have better understanding of how to deal with customers with dementia. **(Receptionist)**

The training was a good insight into understanding dementia and the daily struggles people suffering with it have. **(Pool assistant)**

Excellent training for my staff to raise awareness of a variety of disabilities. **(Manager)**

The training for my staff was excellent and really helped us keep an eye out for anyone who needs support and kept it at the front of our priorities. **(Centre manager)**

The Dementia Awareness Training I found to be one of the best, informative training sessions in a long time. It is also good to know that staff in Bristol's Leisure Centres have gone through this training. **(Linkage worker)**

There were comments that training could be better tailored for the needs of different roles throughout leisure provision such as receptionists versus lifeguards, in order to improve relevance and reduce time and costs. Some centres have made these kinds of modifications. However, Dementia Friendly Training has proved highly successful. The quality and understanding of staff in all social and health care settings provide the foundation for good service delivery. There is little doubt that with almost 900 more professionals now trained to understand and help people with dementia in a leisure setting, there is a stronger platform for programme success and this continues to improve.

Swim England is also aware that the cascade trainers are continuing to train their peers and so the reach of the training is likely to be greater over time. The need for this level of understanding, empathy and patience applies to many vulnerable, unfit, inactive, or unhealthy groups who are not used to venturing into leisure centres and swimming pools. Although Swim England do not have direct evidence, it is likely that the continued exposure to Dementia Friendly Training exposure is improving the chances of successful engagement of people with other health conditions, such as those who are overweight or obese, who are diabetic or have heart problems, and those at risk of falls, which represents a fantastic achievement for this project and a lasting legacy of change.

Figure 6: Understanding Dementia in a Leisure Environment Training During the Launch of Year 2 Sites

2. Improving the swimming environment

In order to extend our expertise for assessing and supporting modifications to swimming facilities for PwD, in Year 1, Swim England engaged the services of Dementia Design Consultancy (DDC) who specialise in the improvement of spaces and services for PwD. This work has produced a guide and an assessment tool for appraising the dementia friendliness of a leisure centre entitled *Is your leisure centre dementia friendly: An environmental analysis and change tool*.

The tool provides a method of assessing entrance and lobby, reception, changing rooms and locker system, showers and toilets, and the swimming pool for ease of usage for PwD and their carers. Critical guidance on issues such as signage, access, clarity, and simplicity of the journey, learned through hands-on research is available for centres launching DFS.

102 sites report having used the assessment tool and some have involved PwD and carer tours in the assessment of accessibility. The outcome is that most of our DFS pools have made changes, but the degree of which has been dependent on need and available resource.

Interest has been shown by Sporta, the umbrella organisation for leisure and culture trusts, in the adoption of this tool for widespread use across leisure services. This organisation covers 493 pools.

The most common modifications:

- Temporary free standing signage and pop-up banners brought out for dementia sessions.
- Permanent indoor and outdoor signage indicating directions to and from locations such as pools, toilets, changing rooms and exits.
- Consideration of colour, size, images, wording and level above ground of all signage.
- Use of same dementia logo in signage as used in publicity materials.
- Footsteps marked on floors directing people to changing room facilities and the swimming pool.
- Simplification of door codes and methods of access.
- Simplification of locker systems and the eventual development of the locker saddle (described later), wrist bands, larger number plates.
- Improved direction and access to the pool.
- Addition of grab rails and towel hooks on poolside.
- Less severe lighting.
- Addition of relaxing music and removal of loud pop music.
- Use of staff uniforms to make them more visible and identifiable.
- Provision of extra seating at key points for carers and people with dementia waiting for sessions.
- Removal of all 'clutter' around the centre.

Figure 7: Moss Side Corridor to Pool, before (left) and after (right) the additional signage was installed.

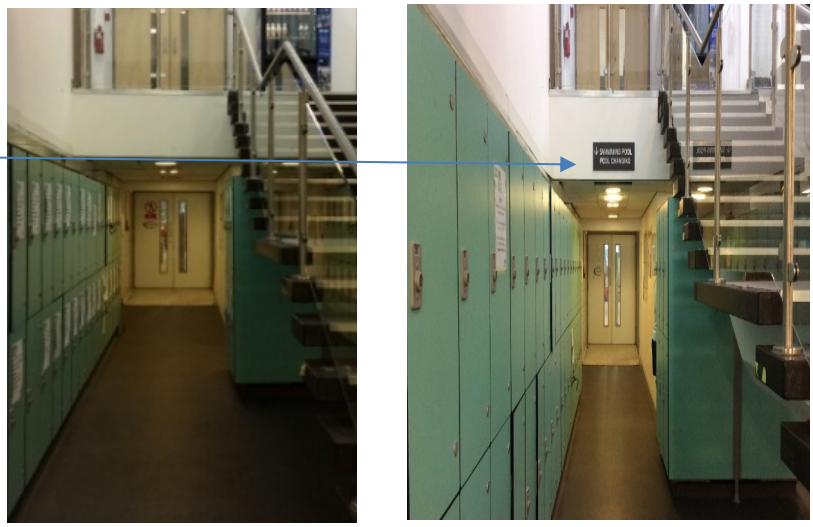


Figure 8: Wythenshawe Forum Way to Swimming Pool, before (left) and after (right) the additional signage and equipment was installed.

Examples of additional signage placed across the city's pools included 'Way Out' and directional signs to the toilets, pool, showers and changing area.

Operators have indicated consistently that DFS has alerted centres to the need to take a more considered look at these kinds of environmental details which they now see as an ongoing improvement process. Interviews indicated that many operators felt that they now see that further improvements are possible and that appraisal should be a continuous process. Pools have commented that the changes made have also benefited people with other conditions such as visual impairment, mobility and balance problems, learning disabilities, autism, and where English may not be a first language.

Case study

At Clifton Leisure Centre the swimming group which included people with dementia and their carers were consulted on signage and additional provisions they felt would improve facilities. The project officer, area manager and duty manager walked through the changing rooms with a group of seven participants. The group not only identified the need for signs throughout the changing rooms but also provided valuable insights into the placement and types of signs including a combination of pictorial and text signage. They also provided other useful recommendations including the installation of hooks for towels/toiletries near the showers and benches to place equipment/sports bags so that people didn't have to place and lift possessions from ground level. The consultation process was extremely useful and the leisure centre aim to meet all of the recommendations of the group

- Nottingham Dementia Friendly Swimming report, October 2017

3. Provision of central resources and support for Dementia Friendly Swimming

The phased design of the project and continual qualitative and quantitative data collection, analysis and feedback have allowed us to develop, review, and refine supportive resources that are unique to the Dementia Friendly Swimming Project. Together these resources are available on the Swim England website as the Dementia Friendly Swimming Hub: www.swimming.org/dementiafriendly/resources

Since the project began the website has been visited by 7,814 unique users with a total of 9,879 visits and 25,969 page views.

Dementia Friendly Swimming resources available to Leisure Services enrolling in the programme

Planning and project administration:

- **Project plan template** designed to provide a guiding framework for the development of new DFS schemes.
- **Terms of reference** template.
- **Service Level Agreement** template.
- **Guidance case studies** for forming user groups, steering groups, recruitment and retention of participants and programme delivery.
- **Case studies of eleven DFS schemes** provide opportunities to learn from the DFS programmes already underway and include descriptions of the models of delivery at our Durham, Manchester, Nottingham, Crawley and Bristol sites.

Marketing materials

- **Your Stories -** news items pages to record and share the growth of DFS, encourage shared learning and increase a sense of unity among scheme promoters.
- **News items pages** to record and share the growth of DFS, encourage shared learning and increase a sense of unity among scheme promoters.
- **Dementia Friendly Swimming Icons**, logo, marketing templates and collateral to take advantage of the DFS brand to jointly increase its national exposure.

Support in changing the environment

- ***Understanding dementia in the leisure environment*** provides downloadable guidance for different staff roles in leisure centres and pools.
- ***Is your leisure centre dementia friendly?*** A guide and assessment tool for improving leisure facilities for people with dementia.
- ***Tailoring the offer guidance*** – *case studies on examples of opportunities being delivered.*

Monitoring and evaluation

- Standard **monitoring and evaluation documents** for the research element of DFS.

Swim England, in conjunction with the Dementia Design Consultancy, has also developed and tested the **DFS locker saddle** which is a specially designed system for PwD to safely and memorably store belongings while swimming.

Figure 9: Dementia friendly Locker Saddle

The locker saddle is a personalised, removable item that aids swimmers with dementia in locating their locker with speed and ease. The saddle is made from a flexible, hard-wearing plastic and hangs over the top of the locker door, both on the inside and the outside. It is personalised for the swimmer, mainly via a clear pocket on the outside flap which enables the user to add any personal image, such as a photo or postcard, or a picture, allowing them to find their locker quickly. The part of the saddle hanging inside the locker has a pocket for a phone, or other personal items, and also some hooks enabling small items, such as keys, to be hung up, to be more visible, and therefore easily locatable. These have recently been produced and distributed to all pools involved in the project and Swim England will be monitoring their use going forwards.

These supportive resources and regular meetings of scheme coordinators have facilitated the organic growth of a shared culture among partners.

4. Establishing partnerships and outreach

In the early stages of the project Swim England recognised that if DFS was to succeed, strong external partnerships with charities and agencies with experience supporting PwD was essential. This required a way of working that was relatively unfamiliar to many in the leisure and sport sector. The skills required to establish outreach to new and challenging groups are quite different from those involved in the management of leisure facilities and provision of activities and sports. However this is precisely what is required if leisure services are to fully engage in solving public health problems such as inactivity, isolation and poor mental and physical health.

There was a particular need to team up with organisations with expertise and experience of developing programmes for PwD. They have regular interaction with this population, understand their needs, can sometimes predict barriers and difficulties, may be able to provide ideas and resources for engaging them and in some instance can support the recruitment of new participants. In this regard, the Alzheimer's Society has been particularly central and Swim England has enjoyed a close working relationship with the Alzheimer's Society at a national level. There is strong evidence from the DFS project reports to show that this has been replicated at local level. For example, the Nottingham evaluation report concludes: "*The support and expertise of delivering the project through the Alzheimer's Society has been invaluable in terms of consultation, insight, training and access to service users and carers*" (Nottingham Final Report 2017).

All but three of the schemes (Bristol, Crawley and Lincoln) have been initiated through local leisure providers and their scheme coordinators have developed either advisory boards or steering groups to help them build their DFS programme. Besides the Alzheimer's Society, partners have been drawn from a diverse range of public and private organisations and charitable trusts including local branches of Age UK, Young Onset Dementia Services, housing providers, Adult and Social Care Services, council officials, community health nurses, and local care providers and carer organisations.

Other partners include *Singing for the Brain* groups and *Dementia Friends Trainers*. *Dementia Cafes* support has been received from at least five Clinical Commissioning Groups (Bristol, Manchester, Durham, Nottingham, and Salford) and we are seeing further relationships building so that this becomes the norm rather than the exception. In addition, DFS schemes are included in at least eight Dementia Action Alliances (DAA) across the country and Swim England continues to encourage more leisure partners to join their local DAA and commit to working towards becoming Dementia Friendly. DFS is also part of Dementia Friendly Communities projects being delivered by the Alzheimer's Society across the country including Hulme and Harpurhey in Manchester, Barnard Castle in Durham and communities in Crawley. In some areas, partnerships with transport providers to help overcome barriers to attendance have also been successfully developed.

Three schemes were unusual in that they have been led from outside leisure services:

- The Lincoln-based DFS scheme is headed by the local Alzheimer's Society branch. The project officer felt that the scheme benefitted from a perception of trust from service users in the name of the Alzheimer's Society and that the project was promoted for well-being rather than commercial gain.
- In Crawley, the initial contact by Swim England was made through Crawley Dementia Alliance who already worked in close partnership with Freedom Leisure at the K2 Crawley site and hosted several Living Well with Dementia events. The alliance is a partnership between Crawley Borough Council and 50+ membership including Alzheimer's Society, Public Health and Crawley Clinical Commissioning Group as well as shops, banking, transport and others across the town.

- The Bristol scheme was initiated through Public Health office. The coordinator used connections across the city and in particular with Linkage the local charity for older adults. They assigned a worker who was successful in recruiting people to the point where Linkage now has a sense of ownership with the project.

These three cases indicate that there is extra benefit from the availability of expertise and connections that come with agencies already engaged with PwD and their carers.

Working partnerships take time to develop and mature but their significance cannot be overstated. Leisure services have traditionally had very limited experience of working with special health needs groups and the organisations connected to them. For DFS to reach this point of success, local leisure coordination teams have invested time and effort that in most cases has been unbudgeted and unexpected. However, the result in all cases has been stronger links with health and social services. Such teamwork builds understanding and helps bring leisure services into focus for other ventures that require close working with care commissioning groups and populations such as older adults, or people with obesity, diabetes, mental health challenges.

As part of the evaluation a survey for non-leisure partners involved with DFS was conducted. The survey attempted to assess the benefits and consequences of working with a DFS scheme. Some surprising and unexpected benefits emerged which help to cement longer term connections with leisure. These are described in greater detail in Section C part 3.

Benefits of partnerships identified by projects

It was really important to have a range of partners, including people/organisations with expertise and experience in leisure, people with expertise and experience working with older people and people with expertise and experience with people with dementia. **(Bristol DFS Coordinator)**

*In January 2015 at the first steering group meeting my thoughts were 'What a lot to achieve!' but now in September 2017 it looks like it has been a success and the project is embedded with the relevant stakeholders. Onwards and upwards! (***Project Steering Group Member, Manchester)**

There has been an increase in partnership working across the city of Manchester. Lots of good relationships have formed. **(Project Steering Group Member, Manchester)**

The project has inspired other to look at their offers for other community groups such as stroke survivors. **(Project Steering Group Member, Manchester)**

Nottingham City Council we will be delivering Swim Inclusive public swim sessions across all of their 7 leisure centres. Some of these sessions will have the added benefit of a pool helper. People with Dementia and their carers will be signposted to these swim sessions as they will be typically quieter sessions with the added benefit of the pool side helper. **(Coordinator Nottingham)**

5. Developing marketing and recruitment strategies

Although there has been no shortage of willingness by leisure and aquatic services across England to start DFS schemes, throughout the project, recruitment of participants has proved to be the toughest challenge. This is not surprising for several reasons:

- It is well established that populations with poor health have proved difficult to engage in all health promoting behaviour change programmes.
- Only a minority of people with dementia have been regular swimmers in their earlier years and so are not looking for swimming opportunities.
- People with dementia have particular difficulties which besides memory loss and confusion include lack of confidence and anxieties, especially in unfamiliar situations.
- People with dementia rely on carers and in most cases the offer has also to appeal to them. This is made more difficult when a person has several carers.
- Leisure centres and pools tend to be noisy and busy public spaces which add to anxieties.
- Leisure centres and pools do not have a strong tradition of accommodating people with health problems and are often seen as 'sporty' venues.
- Research with older adults indicates that more intensive efforts than usual are required to attract them to new programmes.

Because of these challenges, from early in the first year of DFS, sustained research efforts have been made to collect qualitative and quantitative data to provide ideas and strategies for increasing recruitment of PwD to the DFS programme. These have included:

- A search of the limited scientific literature on physical activity programmes for people with dementia.
- Baseline questions on recruitment routes for existing recruitees.
- Telephone interviews with care providers and organisations working with people with dementia.
- Engagement of local advisory groups.
- Regular exchange among scheme coordinators regarding successful approaches.

This work has allowed Swim England to learn and evolve strategic guidance for new schemes in their attempts to establish PwD groups.

Traditionally, leisure services have relied on digital and printed media distribution as their main marketing strategy including posters, pamphlets and flyers, press releases and news items for the media, community newsletters, and more recently social media. Our project reports indicate that this approach has continued to be heavily used through the DFS schemes. Scheme coordinators have worked hard to deliver information to a wide range of local agencies that come into contact with PwD. In several cases thousands of leaflets (for example, 8,000 in Manchester, 2,000 in Nottingham) have been delivered to doctors' surgeries, libraries, care homes, public buildings, community centres, charities, housing services, and distributed at events. These sources of publicity provide an important platform for increasing general awareness and setting the scene for the DFS offer but apart from a small number of cases, have been found to be insufficient on their own. The recruitment figures from Nottingham and Manchester illustrate the point.

Through the marketing journey, lessons have been learned about how best to present the DFS offer. For example, partners have suggested that publicity should avoid focussing solely on 'swimming' as this will deter people who feel they do not swim well. Emphasis should be on the health and wellbeing benefits of being in the water and that all can enjoy regardless of current swimming ability. Images of people already benefitting from schemes and reassurance about being looked after by staff who are DF trained also helps. We also learned how important social aspects of the programme were to participants and that meeting new people and sharing time with them needed more prominence in all publicity and face-to-face marketing.

The scheme evaluations show consistently that the bulk of recruitment (around 52 per cent) is a result of face-to-face contact at settings where groups of PwD gather and through agencies and charities whose business it is to support PwD. This is why partnership development has been such a crucial part of the work of DFS. Our interview work has also indicated that almost all recruitment has either been initiated or facilitated by the carer. This has drawn attention to the need to target carers as much as PwD.

Table 1: How Participants Heard about the Project

HOW I HEARD ABOUT PROJECT	Nottingham PwD and carers combined	Manchester PwD and carers combined
Word of mouth - friend/family	6	10
Health Organisation - GP practice/hospital	5	5
Local Council - social services/support worker	0	1
Carer(s)	0	12
Dementia/Age related charity	32	10
Online Information - internet/website	0	0
Social media - Facebook/twitter	0	0
Printed media - newspaper/newsletter/ leaflet/magazine	0	6
Other media - radio/TV	0	0
Leisure centre/swimming pool staff	0	7
Person I care for told me about it/asked me to bring them	0	0
Other	0	6
TOTAL	**43**	**57**

As Swim England have learned more about outreach and partnerships, recruitment rates have been increasing. For most schemes the largest numbers of participants have been recruited through existing dementia support services and networks, social services, care homes, or as a result of the coordinator visiting other existing groups of PwDs created by Alzheimer's Society or other carer organisations and charities. Recruitment as a direct result of media and print publicity varies among schemes but usually makes up about 10 per cent although it undoubtedly also helps spread the word and assists other recruitment routes. Surprisingly, less fruitful routes have included GP surgeries or contact with other health professionals. Recommendations through word-of-mouth, usually among carers, add significantly with time (around 25 per cent).

Specifically, following strategies have been noted to be beneficial:

- In person visits to established groups where people with dementia meet such as care homes, social events, assisted housing, Memory Cafes, community centres and activity sessions.
- Preparation of specialist publicity materials that can be left for people with dementia to spend more time over and that address concerns, needs and potential barriers.
- All publicity needs to consider the carer as a key player in recruitment.
- Provision of visual aids where possible such as videos of the journey through the leisure centre and of the sessions.

- Clear indications that sessions are relaxed, self-paced, and do not require high swim ability.
- Setting up taster and walk through sessions for groups and providing transport.
- Facilitating word-of-mouth recommendations through use of testimony, case descriptions, and short presentations/videos.
- Keeping partners informed about new sessions and asking them to regularly publicise them.
- Opening sessions simultaneously at several pools to maximise use of blanket publicity.

In our end-of-project interviews participants suggested that sessions need to be advertised more in doctors surgeries as doctors and health professionals are trusted by participants and their families. It may be that further work needs to be undertaken to get health professionals to promote the scheme directly other than relying on flyers in GP surgeries.

Recruitment to DFS has required new ways of working for those schemes led by leisure services and trusts. Developing partnerships and making personal appearances to venues and groups which are unfamiliar are time intensive and demanding, especially when this degree of outreach has been rarely seen before. Often it has required more time and resource than anticipated. However, considerable efforts have been made, lessons have been learned, and this is paying off in terms of growth of DFS.

Survey of care providers

Advisory partners suggested that care provider organisations may be a useful way of developing recruitment and access of PwD to the Dementia Friendly Swimming schemes. At minimum they may offer opportunities for making groups aware of DFS but also there is potential for developing a recruitment route.

Swim England commissioned Continuum to create a custom-design a telephone survey to find out more about how this might be achieved and how any barriers might be overcome. In total, 126 organisations were contacted as part of this research with 40 interviews being conducted. Among those organisations contacted were residential care providers (care or nursing homes), domiciliary care providers which support people in their own homes, service and activity providers such as Alzheimer's Society, day care centres, other charities that bring together groups, and carer support organisations. The purpose of the interviews was to:

- Understand what activities are currently available for people living with dementia and their carers.
- Understand the barriers preventing care providers from bringing groups of people to Dementia Friendly Swimming.
- Gauge interest in Dementia Friendly Swimming.
- Assess the type of support needed to enable participation in Dementia Friendly Swimming.

Findings indicated that many organisations provided PwD with opportunities to get together. Most were social such as dementia cafés, coffee mornings, bingo, arts and crafts, singing for the brain, and watching movies. Where physical activities are offered, they tend to be indoor low-impact activities such as armchair aerobics, yoga, skittles and dancing. Swimming was not offered and had not been seriously considered.

Successful activities were almost always taking place in the late morning or early afternoon with 10am proving unrealistic as PwD take time to get organised in the day and tend to tire by mid-afternoon.

For people living with dementia, and their families/carers, the main barriers to engagement were identified by respondents can be seen in the table below.

Table 2: Barrier and Mitigations

Barrier	Challenge	Potential mitigation
Transport	Those dependent on public transport struggle to reach pools without good transport links. Some people live alone or have carers who can't drive.	Use pools with good public transport links. Target providers who can provide access to transport schemes.
Awareness of opportunities	People with early on-set dementia may not be looking for activities promoted as dementia-friendly. Carers/families & centres don't know the range of suitable physical activities that are available locally.	Provide centres and support organisations with all the logistical information they need to confidently promote opportunities – times, equipment, staff numbers/training, types of activity etc.
Familiarity with swimming	It will have been a long time since some people swam last, so their capabilities or confidence may have fallen. Living with dementia can amplify the anxiety that people have about going swimming. Family members may have concerns about safety.	Initially target the marketing at people more likely to be interested in going to the pool – those already familiar with swimming, or at least comfortable with being in water. Offer water-based activities suitable for non-swimmers.
Unfamiliar environment	Potential participants are unlikely to be looking out for new opportunities. Dementia increases the anxiety caused by unfamiliar people and locations. Using lockers and changing facilities can provide practical challenges.	Share photos and videos showing the centre – reception, the walk to/from the changing rooms, the pool etc. Offer 'come and try' open days, and non-pool activities that build familiarity with the facilities & staff.
Safety	Concern that there is enough staff, with the right level of training, to understand and respond to the needs of participants	Visit centres and meet with potential participants and their carers/families, to answer questions and reassure.

The above information was circulated to scheme coordinators and use to increase contact with a wide range of providers. This proved to be an important source of recruitment as the programme progressed.

6. Tailoring provision

Prior to this DFS project, little was known about the needs, expectations and preferences regarding water-based activity for people with dementia. Schemes have had to experiment, adjust and adapt their provision. Facilities vary in what they can offer with some locations limited to swimming lanes, while others have separate pools for training or aquatic exercise pools. Some pools are found in older (sometimes Victorian) stand-alone buildings with few other facilities while others have state-of-the provision with therapeutic spaces and beach-style entry to the water and/or are an integral part of large leisure and sports complexes. Additionally, in most facilities, availability of spaces is limited as they are used heavily for schools and swimming clubs.

Swim England chose to resist a prescribed formula or set model for provision in DFS schemes and prioritise documenting and learning from the successes and challenges of different approaches. The project has learned that a menu of options for centres with an outline of advantages and disadvantages works best as it allows schemes to make informed decisions about what is practicable for their facility. Examples are provided in the Dementia Friendly resources.

For the PwD and their carer, the experience starts with the journey to the facility and the initial entry. This can be daunting especially on the first few occasions and where Dementia Friendly training of staff and modifications to signage have been so important. Also to help build confidence, familiarisation or taster sessions are offered in some centres where PwD can be accompanied through the facility, questions can be answered and specific concerns and needs addressed. In many schemes, a DFS representative such as the scheme coordinator, will greet the beneficiary. For some participants, just knowing the site hosts DFS offers enough reassurance. Many people swim independently or with their carers without formally registering as part of the programme with the comfort that dementia is well understood and catered for.

Learning through case reports and feedback from instructors and PwD themselves shows that there are two main forms of delivery.

i. The first is to provide protected space for swimming laps in the main pool. Lanes or an area is cordoned off and used specifically for PwD and carers who chose to join the swim. This approach is popular with the stronger swimmers but in some sessions a qualified swim instructor is either poolside or in the water and assists with learning. A lifeguard who has been Dementia Friendly trained oversees the session. These sessions are usually provided at quiet times and the preferred time seems to be late morning. The advantages of this approach is that it causes minor disruption to other swimmers and is also relatively cost effective to deliver.

ii. A second approach is to provide an aquatics session that is dedicated to PwD and their carers. This takes place in a cordoned off section of the main pool or in a smaller training pool. It is usually more varied involving aquaerobics, relaxation activities (Aqua Relax), water-based games, use of swimming aids, some swim teaching or in some instances just allow informal activity. Such sessions are led by qualified instructors who have been Dementia Friendly trained and have the personality to provide a fun session.

iii. Other approaches have been used where facilities allow. For example beach parties where an emphasis has been placed on recreating and recalling positive memories of the water and swimming (such as recall of holiday experiences). Pool parties have been offered as a format to attract people to their first session.

In addition, research with middle age to older adults has consistently indicated the importance of social interaction through activity and the project has found that this is equally important for PwD and their carers. Development of partner and team activity while in the water is appealing. Availability of social space or a café following activity is proving to add value and social time is usually tagged to the activity session.

There has therefore been a shift in thinking from being restricted to the physical benefits of activity and a move to a more holistic approach where mental well-being, enjoyment, and social interaction have taken priority.

Swim England has also investigated the benefits and disadvantages of integration of PwD with other groups of adults, usually who have other health conditions. As an example, lap swimming sessions can be offered during quiet public swim periods which are usually late morning. A trained member of staff is present and there are options to use additional floatation equipment. This is an important additional element of provision as it addresses the key issue of the integration rather than isolation of PwD. Aquaerobics and Aqua Relax are also integrated in some facilities.

A further development is the introduction of a dementia champion or ambassador into leisure centres. This person may be employed or may be a volunteer. It is proving successful for the creation of DF centres where swimming is one aspect of provision and there are options for other non-water based activities such as modified sports or exercise sessions. The champion will help with enquiries, publicise sessions, ensure that facilities are dementia friendly and generally facilitate greater engagement of PwD and their carers.

Provision for PwD is evolving through the DFS project. Considerable learning is taking place about what attracts people and keeps them attending. More is said about this in section B5.

7. Shared recognition and publicity

Creating cultural shifts requires organic and incremental growth. Staff and managers have to buy in to new ways of working and this requires a strong belief in the value of the new venture and often extra time and considerable effort to make it work. This is particularly the case in the early stages when the programme is not well known. Swim England has been active in creating a national brand for DFS so that all schemes can capitalise and encourage a collective sharing of success. In order to help coordinators make the most of the growing prominence of the DFS brand, the service of Dementia Design Consultancy was engaged to produce a memorable icon to represent the DFS programme (featured on the title page). Marketing templates were also added to the DFS Toolkit and questionnaires and information materials standardised.

Figure 10: Minister for Sport and Civil Society Tracey Crouch attending the Launch of Year 2 cities

Section B: Growth of Dementia Friendly Swimming

The information presented in this section has predominantly been extracted from data collected across the schemes (33 sites) engaged in Years 1 and 2 of the programme as these are better established and more data are available. Tables provide key insight into the demographics, dementia diagnoses, health and function levels and motivations of those involved in DFS. These are summary figures and a more complete presentation of analyses is available on request.

Most of the data were collected through the registration documents with some repeated questions at six months. However, informal communication channels with participants and carers were encouraged in order to provide regular feedback. Scheme coordinators provided useful summaries of these in their individual area reports.

1. Growth in number of schemes

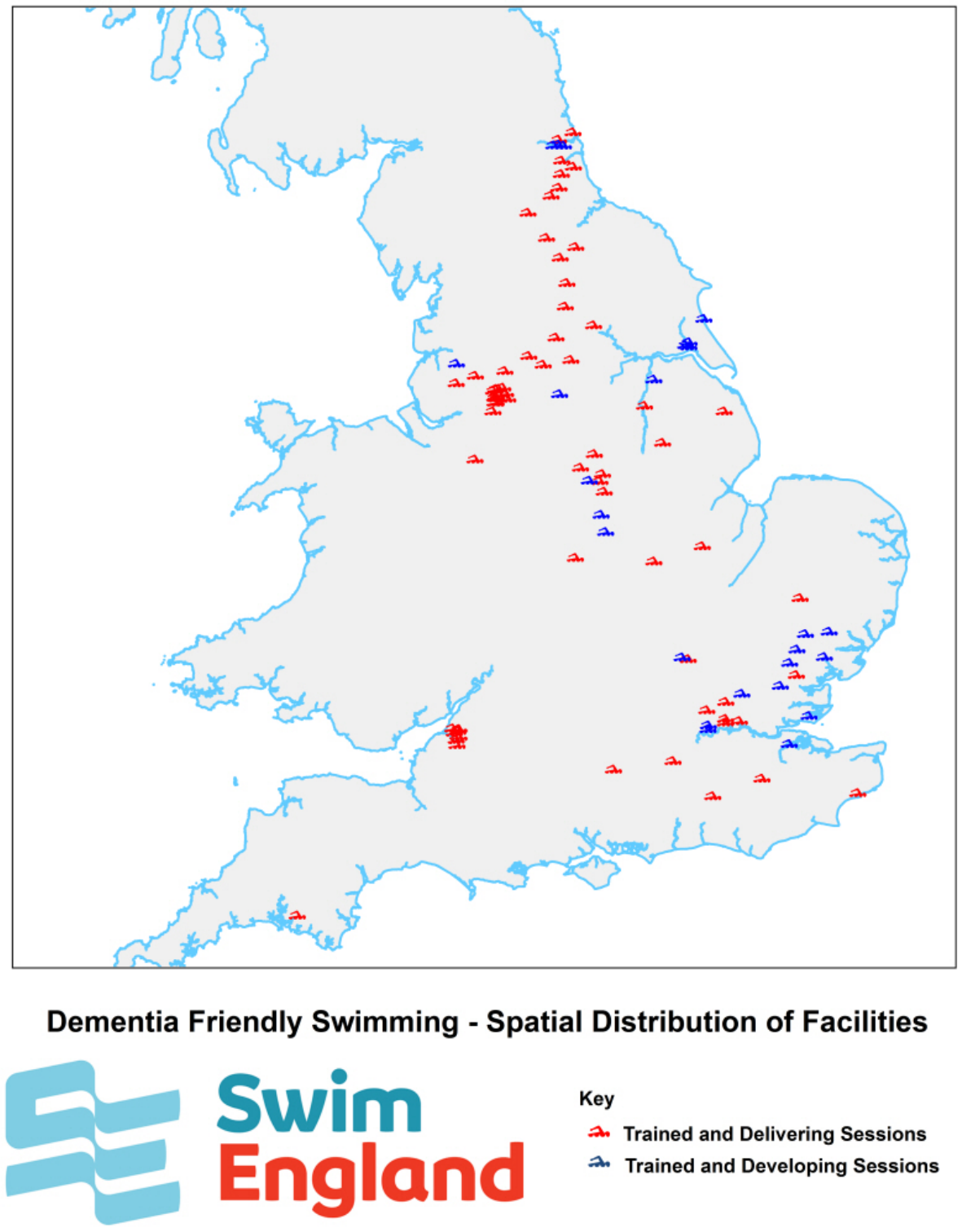
In the spirit of the Department of Health's Innovation, Excellence and Strategic Development Fund, the DFS Project has broken new ground. Swim England has been unable to locate previous UK research that specifically documented attempts to develop swimming and aquatics opportunities for PwD and their carers. The only other known attempt has been a small single-site scheme based in Australia.

With no previous guidance it was logical to start on a small scale and build sequentially, with a strong programme of assessment and feedback to guide learning that could be applied to subsequent stages as larger numbers of schemes were brought on board. The initial proposal indicated that the first year would concentrate on two pilot areas. These were located in Durham and Manchester.

In Year 2 this was extended to a further five areas in Crawley, Nottingham, Bristol, Barking and Dagenham and Tower Hamlets/Hackney. By the end of Year 2 these schemes involved nine leisure providers/pool operators including GLL, Freedom Leisure, Parkwood Leisure and several local authorities and leisure trusts, delivering DFS in a total of 33 pools and by year three 48 pool operators were involved delivering in a total of 102 pools

These figures are interim as more providers are signing up to DFS. Swim England remains fully engaged in extending the DFS scheme across the country as part of the planned, national roll out beyond the Department of Health funding period.

Figure 11: Distribution of Dementia Friendly Swimming Pools



2. Numbers of Dementia Friendly Swimming people recruited

This section of the report focuses on all people who completed the registration process for the programme in Years 1 and 2. Some sections also include information from Year 3 schemes where data are relevant. The total number of participants and carers has grown steadily over the three years of the programme.

Table 3: Number of Registered Participants and Carers

	Year 1	Year 2	Year 3	Total
Number of people with dementia	16	101	414	531
Number of Carers	11	63	261	335
Totals	**27**	**164**	**675**	**866**

The largest growth can be seen between Year 2 and Year 3 which highlights the time it takes for the embed and grow.

The figures suggest that almost three times as many people with dementia as carers have been recruited. In Years 1 and 2, 74 per cent of respondents stated that they attended DFS with a carer and in Year 3 (due to pools not registering carers) it has been assumed that three out of five of the participants attended with a carer.

Numbers of participants – Dementia Friendly Swimming people and carers by scheme

Across the three years of the programme, the highest number of participants and carers were recruited by both of the Year 1 pilot areas (Durham and Manchester), both of whom had the benefit of recruiting over a longer period. Two of the Year 2 areas (Bristol and Nottingham) and one of the Year 3 areas (North Yorkshire) have also recruited a relatively high number of participants.

There is important context to consider; the North Yorkshire scheme covers several pools across a large area and so cannot be compared with the recruitment rate at individual pools. The Lincoln area which started in Year 3 and is smaller by comparison, has been a very successful recruiter and at least ten of our Year 3 areas are already achieving better figures in their first six-nine months than our two Year 1 pilot areas were achieving at the end of their first year. This indicates that they are benefitting from DFS gaining expertise in strategy, supportive resources and greater presence.

As of December 2017, it was estimated that the project had reached a minimum of 1,276 people. This included 531 dementia participants and a further 745 with mixed conditions who had attended dementia only sessions. 531 people with dementia also attended other activities and events.

Estimated reach of Dementia Friendly Swimming

There is limited information regarding what might be expected in terms of recruitment rates for DFS. Numbers are constrained by the prevalence of mild to moderate dementia among the local population. This figure is further constrained by the percentage who are not prepared to consider swimming as an activity. The challenge then is making the receptive remainder aware of the local DFS scheme and making it attractive enough and logistically possible for them to attend.

The Crawley scheme estimates success with 1.6 per cent of the local dementia diagnosed population and 2.1 per cent of the 'living well with dementia' population. The Bristol scheme set their target at 1.5 per cent of local people with dementia which they reached with their 44 participants. The Durham scheme set their targets roughly at 1.4 -2 .4 per cent of the total number of people living with dementia in their delivery areas. Having achieved a total of 69 participants they conclude that 2 per cent is a realistic aim.

Now that partnerships and recruitment links are better established in many schemes after benefitting from the learning and the stronger presence of the DFS project as a whole, attracting 3-4 per cent of the dementia population in an area seems a feasible future target.

Extended reach as a result of Dementia Friendly Swimming

In addition to this data for people with diagnosed dementia, we are aware of several DFS schemes (Crawley and Manchester) where the team have gone on to work more closely with other sectors of leisure services to develop a more comprehensive programme of Dementia Friendly sport sessions.

Furthermore, as we did not stipulate to Year 3 schemes how to organise and deliver the sessions, several operators have chosen to provide mixed sessions for people with a range of long term mental and physical health conditions. They see this approach as a more cost effective way of increasing use of facilities by health needy sectors of the population. Our feedback from scheme operators indicates that this would amount to an additional 745 people.

Although these people do not necessarily have dementia, their attraction to centres is a direct result of the influence of DFS. **This suggests that the total reach so far by inclusion of these extra participants is estimated at 1,276 health needy individuals and the numbers continue to grow.**

3. Characteristics of Dementia Friendly Swimming participants and carers

Our most complete and reliable data arise from the seven Year 1 and 2 schemes from which the figures in this section are derived. The limited Year 3 data that we have captured suggests that there are no great differences in recruitment characteristics from participants in previous years.

Demographic profile

Gender: Data (n=212) collected from the first 3 years of the programme indicates that 53 per cent of PwD were male with the larger schemes showing a fairly even gender distribution. There are some anomalies in the smaller schemes such as Barking and Dagenham and Peterborough being predominantly female and North East Tyneside predominantly male. Currently there is no clear explanation for this but it may be a result of different recruitment routes. In contrast to PwD, only 14 per cent of carers were male and later data on their relationship with the PwD they are caring for suggests that female family members are largely responsible for supporting DFS visits.

Age: Of the 212 participants and 145 carers who registered with the Year 1 and 2 schemes, more than 80 per cent were over the age of 65 with 20 per cent under 65. There are two registered participants aged between 35-39 years, both having had long term mental health conditions rather than a dementia diagnosis and were permitted to join. This suggests that a combination of people with mental health challenges and PwD might work well together for some sessions and help increase recruitment. As might be expected, there was a greater range of ages of carers. Just over half of all carers were over the age of 50 while one in 10 were under 35.

Ethnicity: Around 90 per cent of PwD (n=192) defined themselves as White. Hackney and Tower Hamlets provided the exception with 47 per cent of participants declaring themselves as Black or Black African/Caribbean or Black British, which is reflective of the larger BME population in these areas. Other schemes (Bristol) attempted to engage ethnic minority populations with little success to this point. Similarly 80 per cent of carers (n=87) who engaged with the programme defined themselves as White.

Education: This question was posed to participants only. Education level attained provides an indication of social class and this varied considerably across sites, presumably a reflection of the levels of deprivation and affluence from which recruitment drew.

Table 4: Education Level of Participants

Education Level	Durham	Manchester	Bristol	Barking and Dagenham	Crawley	Notts	All
Primary School	10%	17%	10%	0%	0%	0%	8%
Secondary School	41%	56%	33%	100%	67%	71%	53%
Further Education	18%	22%	29%	0%	33%	29%	21%
Higher Education	31%	6%	29%	0%	0%	0%	18%

The majority (53 per cent), finished their formal education after secondary school. This is not unusual for this generation who are mainly in their 70's and 80's. Participants in Bristol had the highest levels of education, with 29 per cent having studied in higher education.

Living arrangements: Participants were asked to indicate from a checklist which descriptor best reflected their current living situation. There were 133 responses from the seven areas from Years 1 and 2 of the programme. The question was not asked to carers.

Table 5: Living Arrangements of Participants

Living Arrangements	Durham	Manchester	Bristol	Barking & Dagenham	Crawley	Hackney & Tower Hamlets	Nottingham	All Participants
Living alone or with partner / family and I am independent	17%	21%	-	60%	63%	18%	91%	36%
Living alone or with partner / family with support from external carers	13%	6%	-	0%	25%	9%	0%	8%
Living alone or with partner / family with no external carer support	19%	12%	-	0%	0%	0%	0%	10%
Live in residential care or nursing home	44%	53%	-	40%	13%	46%	0%	37%
Live independently in supported accommodation	8%	6%	-	0%	0%	27%	5%	8%
Other	0%	3%	-	0%	0%	0%	5%	2%
'-' denotes no data collected								

The majority of respondents either live in residential care or a nursing home (37 per cent) or are living independently, either alone or with someone else (36 per cent). There was diversity among schemes which probably reflects methods and sources of recruitment. For example, in Nottingham, 96 per cent of participants were living independently either by themselves, with a partner or in supported accommodation. Manchester attracted the highest percentage of participants who lived in residential care homes (53 per cent).

Type of dementia and time since diagnosis

A total of 108 participants from the seven schemes that started in Years 1 and 2 provided a response regarding the type of dementia that they have (23 of whom stated that they did not know). As reflected in the prevalence data, the majority were had Alzheimer's disease or vascular dementia. Time since diagnosis of dementia indicated a wide range with 25% being diagnosed within the last year, 48 per cent between one and three years, 15 per cent between three and six years and the remaining 13 per cent having a diagnosis for more than six years.

Table 6: Type of Dementia of Participants

Type of Dementia	Number of PwDs	% of Respondents
Alzheimer's	52	48%
Dementia with Lewy Bodies	3	3%
Frontal Lobe	4	4%
Vascular	16	15%
Korsakoff	5	5%
Postural Cortical Atrophy	1	1%
Cognitive Degeneration	1	1%
Other	3	3%
Don't Know	23	21%
Total	**108**	**100%**

Perceptions of health and disability

Participants and carers were asked to describe their general health on a scale of 1 (very poor) to 5 (very good) at the point of registering for the programme. Almost half of PwD rated their health as average and a further 36 per cent indicated that it was good or very good with only 17 per cent feeling their health was in a poor state. It seems that PwD attending the programme are at least managing their health and seem reasonably optimistic as a group. Carers rated their general health quite high with 76 per cent scoring at least good.

Table 7: Perceptions of Health of Participants

Self-rated overall health	PwD (n=143)	Carers (n=55)
1 very poor	**3%**	**0%**
2 poor	**14%**	**0%**
3 average	**47%**	**24%**
4 good	**30%**	**36%**
5 very good	**6%**	**40%**

PwD and their carers were also asked whether or not they considered themselves as having a disability, the definition provided being '*a physical or mental impairment that has a substantial and long term adverse effect on a person's ability to carry out day to day activities*'. Of the 129 PwD who responded, 57 per cent considered that they had a disability. Those with a disability categorised them as a mobility impairment (38 per cent), mental health diagnosis which was presumably their dementia (26 per cent) or a hearing or visual impairment (19 per cent).

In addition, a few carers (8 per cent) recorded a disability which was mainly mobility and hearing related. Clearly, consideration needs to be given by DFS scheme coordinators to how these different disabilities can be recorded and accommodated. This includes carers as well as PwD. This level of disability is further highlighted by the perceived need by PwD for extra assistance when getting into and out of the pool. Almost 40 per cent indicated that they would need some help.

Physical activity levels

To gauge activity levels at the point of registration, participants and carers were asked how often they had exercised in the previous four weeks and to include any time when they intentionally raised their heart rate to a state of breathlessness. Of the 165 PwD who responded, 35 per cent reported that they'd exercised once or not at all in the past four weeks. However, a surprising percentage (39 per cent) reported exercising at least once a week with 15 per cent indicating that they were active at least four times per week. These are likely to be PwD who walk regularly. A higher percentage of carers than PwD reported being regularly active.

Table 8: Baseline Activity levels of Participants

Amount of exercise	PwD (n=165)	Carers (n=54)
No exercise in last 4 weeks	24%	11%
Once in last 4 weeks	11%	9%
2/3 times in last 4 weeks	18%	24%
Once a week	8%	4%
2/3 times a week	16%	15%
4+ times a week	15%	33%
Don't know / can't recall	8%	4%

Swimming ability, experience and confidence

To enable those engaged with the programme to be supported in the best way possible, registered participants and carers were asked questions relating to their swimming experience. The first question asked them to specify when they last went swimming for a session of at least 30 minutes.

Tables 9 and 10: Baseline Swimming Figures

Last swim?	**PwD (n=160)**	**Carers (n=53)**
Last 4 weeks	14%	40%
2-6 months	7%	23%
7-12 months	6%	8%
1-5 years	18%	17%
5+ years	28%	11%
Not Sure	28%	2%

Able to swim?	PwD	**Carers**
Can't Swim	14%	4%
Require floats/won't take feet off floor	22%	5%
Can swim 25 m or more	64%	91%

While more than 20 per cent of PwDs had been swimming in the last six months, 46 per cent had not been swimming for at least a year. Also 28 per cent were unsure when they swam last. Carers were more likely to have been swimming recently but 28 per cent had not been swimming in the last year.

These figures are backed up by responses to a question about swimming ability. Although 64 per cent indicated that they could swim 25m or more, 14 per cent reported that they could not swim and another 22 per cent said that they would need swimming aids.

They were also asked about their confidence in the water on a five point scale ranging from very anxious to very relaxed. The majority felt relaxed about getting in the water but a noted minority were anxious.

Table 11: Baseline Confidence in Swimming

Confident in the water?	**PwD**	**Carers**
1 very anxious	5%	2%
2 anxious	10%	2%
3 average	34%	12%
4 relaxed	20%	26%
5 very relaxed	31%	59%

The largest cohorts of non-swimmers and people requiring floats/won't take their feet off the floor were drawn to the programmes that were run in Manchester, Hackney and Tower Hamlets and Durham and Bristol. All of these areas had members of staff in at least one of the pools sessions to support swimmers and carers alike. Crawley, where sessions were completely inclusive, had a comparatively high level of competent swimmers.

Taken together these figures indicated that DFS has successfully attracted many people who have not recently been regular swimmers. A significant percentage has limited ability and lack confidence. This is confirmed by our end of project interviews where several PwD had had little recent swimming experience. The figures also indicate that particular provision is needed for a significant minority who feel anxious around the pool and report low levels of swimming ability. No doubt some of this is down to apprehension at the start of the programme but nevertheless needs careful consideration if all participants are to have that important very positive first engagement.

The recruitment to DFS of a significant number of PwD who have had little or no swimming experience is a significant and perhaps surprising achievement. This is particularly the case as a large percentage seems to be otherwise inactive (35 per cent). Physical activity programmes are traditionally more successful in attracting those who have at least a recent history of being active and who feel reasonably confident about their competence.

Participants and carer relationships

Participants were asked who they planned to attend the Dementia Friendly Swimming sessions with each week. The 135 responses from the Years 1 and 2 schemes suggested a heavy reliance on carers bringing participants to the swimming sessions (74 per cent). Only 17 per cent of registered participants attended the sessions alone. The Hackney and Tower Hamlets and Nottingham schemes had the highest percentages of PwD who attended without a supporter (both 39 per cent).

Carers were asked about the nature of their relationship with PwD who they accompanied. Two thirds of carers were family members with 36 per cent being partners and 16 per cent being a son or daughter, and 16 per cent another relative. Both the Durham (31 per cent) and Manchester (22 per cent) schemes had a high percentage of 'other' carers who were mainly from support services. Therefore there appears to be a good deal of dependence on the close family for supporting PwD to attend DFS sessions.

Carers were also asked whether or not they intended to either swim, or take part in another physical activity at the leisure centre/pool when they brought the person they cared for to the sessions. Of the 92 who responded 77 per cent indicated that they intended to be active. This figure varied between schemes with 62 per cent of carers in Durham and 100 per cent of carers in Bristol and Crawley indicating that they intended to be active in some way. Fifty one of the 71 who answered this way indicated that they intended to swim or join in the DFS aquatics session.

4. Motives and initial beliefs among people with dementia and carers

In order to provide the best possible service for participants, it is critical to understand their motives and expectations as they begin the programme so that they might be managed and where possible satisfied. As part of the baseline registration questionnaire, PwD and carers were asked through a check list to identify the main three reasons why they signed up to DFS. A total of 146 PwDs and 75 carers provided at least one reason and the figures in the following table denote the total number of responses given, as opposed to the number of participants.

Table 12: Motives for Joining Dementia Friendly Swimming

Motivations – Sign Up	Responses from PWD	% of Responses from PWD	Responses from Carers	% of Responses from Carers
To meet new friends	55	15%	14	9%
To get out the house more	47	13%	10	6%
To enjoy swimming	81	22%	15	10%
To relax and de-stress	15	4%	3	2%
To feel better about myself	12	3%	6	4%
To get fit/healthy	38	10%	9	6%
To keep fit / healthy	18	5%	11	7%
To lose weight / maintain weight	7	2%	4	3%
To stay active and mobile	39	11%	4	3%
To increase my confidence	6	2%	3	2%
To have fun	22	6%	7	5%
To be able to swim in a group/with other people	5	1%	2	1%
My carer brought me along to the session	20	5%	0	0%
To be able to do activities with the person I care for	0	0%	24	16%
To bring the person I care for	0	0%	38	25%
Other (inc. ability to still swim after a stroke)	2	1%	4	3%
Total	367	100%	154	100%

For PwD, *enjoyment of swimming*, the *potential of meeting new friends* and the *opportunity to get out of the house* were the most frequently checked reasons for getting involved with DFS. Also indicated by 10 per cent and 11 per cent respectively were *to get fit and healthy* and to *stay active and mobile*. Perhaps unsurprisingly for carers, the most frequently checked reason was to *bring the person I care for* followed by *to do activities with the person I care for.* However, around 11 per cent of carers also regarded DFS as an opportunity to *meet new friends* and *enjoy swimming*. Clearly, it is important that engagement in DFS sessions fulfil the expectations of both PwD and carers and this information guided coordinators to focus on making swimming sessions enjoyable and to offer opportunities for social exchange both during and after sessions.

Perceived benefits of swimming

During the registration process, in order to check the beliefs of participants and carers, they were ask to rate the potential benefits of swimming for wellbeing, fitness and health.

Table 13: Baseline Perceived Value of Swimming

Value of swimming	Percentage of PwDs (n=134)				Percentage of Carers (n=53)			
	Agree	Neither Agree or Disagree	Disagree	N/A	Agree	Neither Agree or Disagree	Disagree	N/A
Swimming is beneficial to my wellbeing	93%	5%	0%	2%	96%	2%	0%	2%
Swimming keeps me fit and healthy	89%	9%	0%	3%	94%	0%	0%	6%
Swimming will be good for my current health	88%	11%	1%	2%	67%	8%	0%	25 %

The vast majority of respondents perceived swimming to be beneficial to their wellbeing, keeping them fit and healthy, and helping with their current health levels. Fewer carers saw that swimming would be good for their current health and these were possibly the carers who did not intend to swim in the sessions. These figures indicate that those who sign up for DFS appear to already convinced that swimming is going to be helpful for them.

5. Attendance at Dementia Friendly Swimming sessions

Number of attendances

Reliable data on attendance is limited to those sites who had robust methods of registration, and this was usually achieved through membership card scanning. The figures provided by scheme coordinators suggest that over the first two years of the programme registered participants and carers visited an average of five sessions per individual. However, throughput was not calculated for 70 participants and carers from the seven areas that joined the programme in the first two years, meaning there is no information for 21 per cent of the people engaged during this time, and the total throughput figures and average number of visits are likely to be considerably higher.

Table 14: Average Number of Visits

Year 1 and 2 schemes	Average number of recorded visits per PwD
Durham (Year 1)	5
Manchester (Year 1)	6
Bristol	3
Barking & Dagenham	2
Crawley	4
Hackney & Tower Hamlet	4
Nottingham	6
Total	**5**

Table 15: Frequency of Attendance in Nottingham

Frequency of attendance in Nottingham between Oct 2016 and Aug 2017				
Percent of sessions attended	**PwD**	**%**	**Carers**	**%**
0%	**0**	**0%**	**0**	**0%**
1-25%	**6**	**27%**	**9**	**43%**
26-50%	**7**	**32%**	**8**	**38%**
51-75%	**7**	**32%**	**3**	**14%**
76-99%	**2**	**9%**	**0**	**0%**
100%	**0**	**0%**	**1**	**5%**
TOTAL	**22**		**21**	

The Nottingham report shows a total of 353 attendees (224 by PwD and 130 by carers) at the swims sessions between October 2016 and August 2017. Forty one percent of PwD attended at least 50 per cent of available sessions. Manchester recorded 373 session attendances by PwD and 228 by carers.

Motivation for continuing to attend

A small sample of 33 PwD and 17 carers who have been engaged on the programme for six months reported their motives for continuing to return to sessions. The baseline checklist was re-administered and three responses per person were encouraged. A similar pattern to motives for signing up is seen. This suggests that at least among this small sample, their expectations and motives have not changed and presumably their expectations have been met. The figures below denote the total number of responses given, as opposed to the number of participants.

Table 16: Motivations to Attend

Motivations to attend	Responses from PWD	% of Responses from PWD	Responses from Carers	% of Responses from Carers
To meet new friends and socialise	12	18%	4	9%
To get out of the house more	15	23%	6	14%
To enjoy swimming	16	24%	6	14%
To relax and de-stress	3	5%	3	7%
To feel better about myself	1	2%	1	2%
To get fit / healthy	3	5%	1	2%
To keep fit / healthy	3	5%	0	0%
To lose weight / maintain weight	0	0%	0	0%
To stay active and mobile	3	5%	1	2%
To increase my confidence	2	3%	0	0%
To have fun	1	2%	0	0%
To swim in a group / with other people	0	0%	1	2%
I only come because my carer brings me	0	0%	0	0%
My carer like to swim	1	2%	0	0%
To do activities with the person I care for	0	0%	6	14%
To bring the person I care for	0	0%	9	21%
I like the staff at the centre	3	5%	3	7%
Other	1	1%	0	0%
Not applicable	2	3%	2	4%
Total	**66**	**100%**	**43**	**100%**

Factors associated with attendance and avoidance of dropout

The programme has accumulated 2.5 years of learning through questionnaire analysis, feedback from participants, sharing at scheme coordinator meetings and summaries of outcomes in scheme reports on what makes schemes successful for participants and what deters them from attending or causes them to dropout. Several factors are concerned with satisfying the motives of participants when they joined and as they continue to attend such as ensuring an enjoyable swimming experience and providing opportunities for friendships to develop.

Also DFS project reports and end of project interviews with PwD and carers are consistent in the reasons they have identified for PwDs continued attendances. These include the welcome they received, the qualities of staff, the opportunity for exercise and physical exertion, the chance for peer support and interaction, and developing a 'sense' of belonging'. Some PwD suggest that part of the reason for attending is to please their carer or provide the opportunity for their carer to either enjoy swimming or the free time it allows.

The reasons for absences provided by participants are also consistent. Doctors and hospital appointments were regularly cited as were occasional bouts of poor health or long term conditions such as muscular or joint pain. Several participants stated that, in some weeks, they are just not in the mood or the right frame of mind to attend. Bad weather was also referenced as a reason for occasionally not making the journey.

Some negative factors were also mentioned in end-of-project interviews. Noise and young people were regularly cited as negative factors by participants so that school holiday time is sometimes difficult for PwD. While some just saw this as a nuisance, others stated that they don't attend sessions when they know there will be a lot of young people in the pool, such as during school holidays. Cold water was mentioned as a problem in some pools to the point that it spoils the experience. Transport difficulties were also mentioned although this was not a widespread problem. Operators also noticed a reduction in attendance during bad weather and in the winter months.

In summary we have learned that the following factors are critical to maintaining attendance and avoiding absences:

- **Empathetic and skilful staff**
  This is common to all effective service delivery in health and social settings. A scheme coordinator identified the need as: "someone who is enthusiastic, caring, understanding, not easily offended or embarrassed, willing to get in the pool and willing to be 'hands on' with people in the water". If the leader is not able to establish positive relationships then the programme is likely to struggle. The feeling is that the leader does not necessarily have to be a swimming teacher, although this is an advantage. Fundamentally it needs to be someone who can make sessions fun and help participants feel confident and safe.

  Good leaders understand and get to know their participants and are quick to build rapport and trust. It is beneficial to see the same face on reception and at pool side each week as it reduces uncertainty and anxiety. The Lincoln scheme felt strongly that a high staff to participant ratio was compatible with high retention. The more one-to-one time that participants received, the more likely they were to keep attending. Some schemes such as Manchester have engaged volunteers and given the title of Pool Activators to help provide support to individuals without raising costs. They meet and greet, help navigate around the centre and being a familiar face on poolside during a session. The Manchester coordinator believes that the help of volunteers has resulted in people attending who would not otherwise be able.

- **An induction that puts people at ease and addresses concerns**
  Misconceptions, misunderstandings, anxieties and uncertainty about swimming in general and the DFS scheme have been a barrier at the recruitment stage and often continue after the first attendance unless care is taken to reassure, answer questions and provide critical information. For example**,** a barrier identified early in the project was a result of concern about swimwear. Knowing what to wear and bring to sessions was a frequent question and advice was needed about how to deal with incontinence. Misperceptions such as pool sides

being extra slippery needed to be addressed. Lack of confidence in the pool in terms of personal appearance and ability had to be spotted and sensitively handled. These may seem small issues but can be of sufficient importance to prevent people signing up (who may not even ask questions) or prevent people returning after their introductory sessions.

- **Improved pool session timetabling and appeal**
  Several lessons have been learned here:
  - Regularity of sessions at the same time same day each week is important.
  - Late morning or early afternoon sessions are popular and evening sessions are not.
  - Warm water is appreciated and cold water is not.
  - Quiet times around the pool are best as sounds can be difficult.
  - Relaxing music is helpful and modern loud pop music is not.
  - Fun, friendship, and learning are the key motivators.
  - Exercise such as Aqua Relax in shallow pools is helpful for less confident swimmers or those who just enjoy being in the water.
  - Where swimmers are not confident, it is important to have a helper in the water.
  - Some PwD are good swimmers and are happy swimming laps in dedicated lanes.

- **Providing opportunities for social interaction**
  Research with older adults has consistently shown that one of the main motives for engagement in physical activity programmes is the chance to meet people and develop friendships. Many DFS participants have confirmed this finding and often they say it is one of the main reasons for attending. Scheme coordinators also attribute attendance success with the social time after swimming. This is helped where locations have cafés and suitable sitting areas. There are examples of friendships developing and leading to other activities beyond swimming.

- **Keeping the feedback channels open**
  Several scheme coordinators have worked hard to seek regular feedback from participants, carers, staff and volunteers, sometimes through cards but also through discussion. This often happens in the social time following sessions. Suggestions provide the opportunity to further enhance the appeal of sessions and nip problems in the bud.

- **Taking measures to address dropout**
  Gathering reliable information on dropout and factors leading to it is difficult in all research. Almost all scheme coordinators report that telephone follow-ups, usually to carers rather than PwD, were used as soon as attendance falls and this was seen as critical to reducing numbers who dropout. PwD are no different from others in that they do not wish to offend and they are likely to be reluctant to reveal the true reasons why they might not have enjoyed DFS. Often there may be good reason that prevents continued attendance.

  A small sample of 15 participants and seven carers who had dropped out, as well as informal reports from scheme coordinators who provided information from follow up telephone calls. The most common reason provided was deteriorating health and worsening dementia which is inevitable with this population who have increased prevalence of co-morbidities such as diabetes, arthritis, and cardiovascular disease. Difficulties with transport and poor transport links have also been given as reasons for giving up. Also having nobody to attend with has been a problem as is the case when the carer changes. Some schemes have teamed PwD with a volunteer to help overcome this problem. More of this kind of information is needed as it points directly to where sessions and programmes might be further fine-tuned to retain participants.

Section C: Benefits of Dementia Friendly Swimming

1. Perceived benefits for people with dementia and their carers

A small repeated measure sample at six months is available through re-administration of the questions about the benefits of participation in DFS. The responses remain very positive as were their expectations at the start of the programme. For this sample it appears that DFS attendance is working to meet their expectations. A large majority of participants and carers feel that participation in the programme is helping their well-being, has increased their confidence and helped them make friends. Some of the most frequently reported benefits are around opportunity for social interaction both within and beyond the group.

Table 17: Perceived Benefits of Swimming by Participants

Perceived benefits of swimming at 6 months	PwD (n=34)				Carers (n=14)			
	Agree	Neither Agree or Disagree	Disagree	N/A	Agree	Neither Agree or Disagree	Disagree	N/A
DFS has benefitted my wellbeing	91%	3%	0%	6%	71%	7%	0%	21%
DFS has kept me fit and healthy	91%	3%	0%	6%	71%	7%	0%	21%
DFS is good for my current health	82%	12%	0%	6%	43%	7%	0%	50%
DFS has increased my confidence	76%	15%	3%	6%	57%	21%	0%	21%
DFS has helped me make new friends	79%	3%	9%	9%	71%	14%	0%	14%
DFS has encouraged me to try new sports or activities	42%	18%	27%	12%	50%	14%	0%	36%

Activity levels and swimming ability

Activity Levels: At six months, 69 per cent of participants indicated that they had become more active overall as a result of the programme. On this occasion, they were simply asked whether or not they believed they were now more physically active than before the programme.

Water Confidence: Participants and carers who completed the six month follow up survey ask again at this point how confident they felt in the pool. A small sample of 32 participants and 12 carers responded, and thus the information should be regarded as indicative rather than a definitive picture.

Whilst drawn from a small sample, the data suggests a trend of improved water confidence amongst both participants and carers since the start of the programme. The proportion of participants rating their water confidence as a 5 (very confident) showed an increase from 31 per cent to 53 per cent and levels of high confidence amongst carers showed an increased from 59 per cent to 92 per cent.

Swimming Ability: A small sample of 37 PwD and 16 Carers were asked whether or not their swimming had improved as a result of taking part on the programme.

Table 18: Improvements in swimming ability

Has Swimming Improved?	PwD (n=37)	Carers (n=16)
Yes	49%	50%
No	27%	25%
Don't Know	24%	12.5%
N/A (Did not participate)	-	12.5%

Approximately half of all respondents responded positively. Whilst this is a small sample, and as such firm conclusions should not be drawn, it does indicate that the programme had some levels success in improving the swimming ability of those who took part.

Health and Wellbeing outcomes

Additional qualitative data was collected from:

- Scheme reports as coordinators and/or session leaders as a matter of good practice seek regular feedback from their participants and carers.
- 15 PwD and 11 carer end of project interviews.
- Detailed PwD case summaries which are featured at the end of this section. Interviews addressed whether DFS had helped with physical well-being, psychological and social wellbeing, and day-to-day life.

Physical wellbeing: An unexpected but widely reported benefit came from people who suffered joint pain and swollen feet. Water-based activity alleviated pain and discomfort. Two participants reported that they felt improvements in balance, one who had taken part in a falls prevention programme. Another participant, who had Parkinson's as well as dementia, was wheelchair bound and, had to use a hoist originally, is now able to get himself in and out of the pool. Most participants pointed to subtle or greater improvements in their physical fitness as a result of going swimming and several reported that their swimming ability had improved. A significant number of the people attending the sessions also have other health issues including arthritis, joint/mobility problems, heart and lung conditions, asthma and high blood pressure. The Swim England health benefits review of evidence suggests that swimming will have a positive effect on each of these even if they are not immediately apparent to the participant.

Psychological and social wellbeing: The interviews produced most comments about mental health and feeling better as a result of taking part in DFS. Swimming and the opportunity to socialise as part of the programme improved mood (particularly sense of joy and happiness). People with dementia are often conscious that they are losing cognitive and physical abilities and several participants report that swimming was one area of their lives where they felt that their confidence and ability was actually improving. Some felt that being in the water made them feel more alert and mentally stimulated and able to concentrate better. There are examples of some people who start the programme feeling very anxious and withdrawn and who eventually develop confidence in the water and also in social interactions. One participant described, that after retirement they became isolated and the programme has "brought them out of themselves again".

Day to day living: Participants did not feel that their ability to independently manage activities of daily living had changed noticeably. Similarly, there were no reported effects on reliance on medication or on healthcare professionals or GPs. There were several references to swimming making people sleep better from both participants and carers and some comments on improvement in appetite. According to some carers, their PwD was now more sociable and more motivated to join groups beyond the swimming group.

These are profound benefits that can be a catalyst to better overall quality of life. Although participants will vary widely in the benefits they experience from DFS, some are quite intense and potentially life changing. One 83 year-old participant who was unable to swim at the start of the programme swam her first length after five months.

Summary of participant comments on what makes swimming especially appealing:

- It is an activity that has a very positive effect on aches and pains, specifically joints.
- There is little chance of getting an injury.
- It is easy to see progress e.g. making it to the other side.
- It is doable even if you can't swim through walking or using the floats.
- It feels liberating and makes you feel good.
- It is empowering and can increase confidence.

Comments from participants

"It's probably the only thing I can do where I'm on my own. I couldn't go for a walk really on my own, or go to the park on my own. Wherever I've got to go, it's either Joyce has got to come, or my daughter has to come."

"I don't do a lot of walking, because of my joints. I wish I could do a bit more walking. But my legs will tend to swell up most of the time. So, I've got joint problems and I don't do a lot of walking. The water just feels great…I don't feel the pain in the water…when I'm in the swimming pool, I don't feel any pain."

"I always feel a lot better after a swim. As if all my joints had been oiled. I think it's the only exercise where virtually all your joints are working."

"I am talking…I usually keep my mouth quiet and listen. I do that because sometimes I may find it difficult to contribute or difficult to say what I want to say…Swimming must help me to get that extra confidence to communicate."

"With swimming, I don't have to worry about whether I'm going to fall or anything like that. It's so wonderful."

"You watch some of the people on the journey, they're gradually going downhill and we're not…It's making us more alert."

Carers also report benefits for themselves. Those who did not swim appreciate the time to socialise and experience the support of other carers. They tended to chat and share experiences. Some felt that the act of enabling an enjoyable activity for their PwD was sufficient reward and made them happy. Those who swim report the same well-being and health benefits as PwD reporting feeling

mentally stimulated and in a better mood. Some also indicate that the sessions have acted as a springboard for other social opportunities. No carers said they were particularly more active as a result of coming to the sessions, but in terms of outcomes, the social and mental wellbeing benefits are clear to see.

Comments from carers about participants

"This is amazing. I never thought I'd see my husband back in the pool and had come to accept that this was yet another thing that we'd 'lost'. But, he enjoys it, he actually eats a meal with everyone else who has attended, which he'll never do anywhere else, and, best of all, because of the physical stimulation, he sleeps, and, because he sleeps, I sleep!" **(wife/carer)**

"It makes him happier when he's in the pool. It makes him more confident. He goes home and he always talks about it to his 3 children, about how much he enjoyed it's a real achievement to him." **(wife/carer)**

"He can't move around ... he couldn't like play football or tennis or anything like that because he can't move about like that. So swimming, I think is the best thing for him. He gets about in the water using just the one leg, because you're lighter in water aren't you." **(daughter/carer)**

"*He's starting to go downhill now… things are just…running their course now. So he's just getting a bit ... He's confused more and stuff, but once he's in swimming, it's like he's not. He knows what he's doing."* **(daughter/carer)**

"Going swimming has definitely improved his balance. He walks with a stick, so it's important for him to get as much exercise as possible. The swimming helps." **(wife/carer)**

"*She came in one day and she could just get her shoe on. By the time we come out the water, all the swelling on her foot and knees had gone down*." **(carer)**

"She started off the first week clutching on the side, wouldn't move…She now does twelve widths across from side to side. I mean she has a little help, but we start at the side where that little sign is…The confidence she has built up is amazing." **(carer)**

Figure 12: Swimmers at Hengrove Leisure Centre, Bristol

Figure 13: Dementia Friendly Swimming Social Activity post-swimming at Hengrove Leisure Centre

2. Illustrative case studies of beneficiaries

Helen, 75 (person living with dementia)

Helen learnt to swim at the age of four and has been an occasional swimmer ever since. She's always been keen to be active, she trained as a yoga teacher in her formative years and enjoyed walking and cycling. Helen is now 75 and was diagnosed with dementia two years ago (gradual onset). She remains very independent, considers her memory to be good and doesn't think of herself as having dementia, preferring instead to describe herself as *'a 75 year old with a few problems'.*

Helen tries to keep active by walking to the shops regularly as she no longer drives. Whilst she was an active cyclist for many years her dementia has notably affected her balance and co-ordination. She is unable to maintain her balance on a bicycle anymore and has experienced a number of falls.

Helen used to attend 55+ swimming sessions but stopped going as she was put off by feeling everyone was much quicker than she was, she recalls an experience in the changing room *'I was hours in there. Damp socks on damp feet'*.

Helen has recently started receiving support from the NHS Dementia Wellbeing Service. Her Dementia Navigator linked her with local carers who have been helping her find new, exciting and interesting things to do in her local area. Given Helen's previous participation in swimming, after a quick internet search Helen's carer made contact with her local leisure centre and arranged to bring Helen to the DFS session. Helen's carer was keen to point out that Helen *'doesn't want to be pigeon-holed because she has dementia'*, however, *'when you have dementia, sometimes being in an environment with other people who understand you... it makes your surroundings a lot better… if she's 'a little bit slower, it doesn't matter. If she takes a bit longer in the changing room, it doesn't matter'*.

Helen relies on her carers bringing her to the sessions. While she intends to swim regularly, she also doesn't like to pressurise herself into committing to doing things, preferring to see how she feels on the day. The things most likely to deter her from attending are the weather, her mood and whether the pool is likely to be busy with any children (she finds noise and busy environments off-putting).

Helen doesn't feel anxious about attending the sessions, but is conscious of not wanting to slip on the tiles and is not overly fond of putting on wet clothes and socks afterwards. She especially enjoys quiet pool time, the jazz music in the pool hall, the pace of activities in the DFS session as well as the support offered by poolside staff.

Helen feels she has gained many benefits from participating in the programme. In her own words: 'with swimming I don't have to worry about whether I'm going to fall, or anything like that. It's so wonderful to be held [by the water]'…. *'it's made me more perky' and 'cheered me up no end'… 'I sleep brilliant' and have 'little power naps',* and in terms of feeling fitter, *'I think I do, I certainly don't feel any less fit'.* She also considers that *'swimming could very well be [good for] mindfulness, because, you know, you're in your own zone.'* Since participating in the swimming sessions, Helen is keen to get involved in more activities, especially yoga and dancing.

Alice, 88 (person living with dementia)

Alice was a recreational swimmer until she was a teenager but avoided swimming until recently when she was encouraged to take part in the Dementia Friendly Swimming Programme by her Activities Coordinator and her *'brother-in-law who's been prescribed these sort of exercises in water'.* Alice is 88 and lives in a residential care home having had a stroke and having developed dementia. Alice has difficulty with her speech, experiences severe pain in one of her legs and has extreme difficulty walking. She is able to use a rollator frame to get around her bedroom and bathroom but any further than this and she is reliant on other people taking her in a wheelchair.

Alice attends the DFS swimming sessions once a week with the Activities Co-ordinator and other residents of the care home that she lives in. They come to the sessions via either a taxi or a mini bus, the costs of which are added to their monthly bills by the care home, and usually stay to enjoy a cup of tea and a chat in the café after the session.

Alice was initially nervous of participating in the DFS swimming sessions because she *'didn't like the hoist'* at the pool. Since then the group has re-located to a pool with walk in ramp access and Alice is able to be assisted into the pool via a poolside wheelchair which she feels much more comfortable with.

Alice has reported numerous benefits from attending the sessions: she considers herself to be more active; her water confidence has grown; and she feels a lot better since she started coming. Alice especially enjoys getting out of the care home, socialising with other participants and likes being in the water. *'A lot of the clients* [in the care home]... *sleep'* but Alice believes that '*it's good to exercise'.* She considers that being in the pool offers her a unique form of pain relief and that the support offered by the water enables her to walk notably further than she can on land.

In her own words: *'I have difficulty walking very much… I have trouble with my right leg, and sometimes I have a pain down the side… walking in the water helps* [with the pain]*… I don't swim in there. I just walk, with help… I'll just say it does make my leg, the pain in my leg easier.... I wouldn't say it lasts forever, but it does last a while after having been in the* [water]*... until the evening. I would say I would be walking more in the water… My son seems to think the day after that I'm walking better... with the zimmer.'*

Alice likes to use the sessions to challenge herself. She walks widths of the pool (aided by the Activities Coordinator, an instructor or volunteer). She started off doing 2 widths and aims to increase the distance each week, where she can. She explains that *'maybe after a few turns, I have a rest, and then start again'*. At the time of writing Alice was very proud of now being able to walk 12 widths and attributes her progression to *'bloody mindednesses!'*, having help in the pool and the fact that *'the people in the pool know what we need'.* She says that *'if there wasn't a group, I wouldn't come… I wouldn't be able to cope, I have to sit in the chair'.*

Alice finds the leisure centre a positive place to be. She feels that the facilities make the experience better, specifically the ramped access and 'the *changing rooms are good, I cope because of the handles... and I have help'*.

Alice is a strong advocate of the Dementia Friendly Swimming sessions and is always trying to encourage other residents of her care home to attend, especially those with mobility problems. She has her sights on encouraging one particular resident *'I told him about it, because sometimes he said to me that his doctors had said that he would lose his walking and he would have to have two sticks or a chair like this, and I said it would help him, like, walking in the water, you know… I told him even if he didn't have a pair of trunks… we would find him a pair of trunks!'*

Martha, 63 (Carer) and Charles, 75 (person living with dementia)

Martha is the full-time carer of her husband Charles. Charles has Dementia with Lewy Bodies and Parkinson's disease and he has been a wheelchair user for almost a year. In the past, Charles and Martha were very active people. Martha recounts that Charles *'was quite a sportsman'.* He played football and squash and was into bikes. '*He used to go to the gym and have a swim afterwards, but about three years ago, he could no longer do it on his own and he needed support. I was fine in the gym, but I don't like water… so, it meant he couldn't go. The gym he used to go to wouldn't provide staff… so, he stopped going'.*

Martha heard about the Dementia Friendly Swimming programme via a leaflet that was in her GP Surgery: *'I go round looking for leaflets because I'm the one he's turned to. And it's come on pretty quickly… I had breast cancer a month after* [he was diagnosed]… *I had to go through chemotherapy and radiotherapy, so by the time I'd come out of that a year later, he'd deteriorated that much, I had to give up work. I couldn't go back to work. And you think, well, what do I do? I'm not sitting in the house all day so I looked. When I go out I look to see what we could do together…. and… anything that would keep the movement up'*.

Martha and Charles drive for 25 minutes to get to the leisure centre and have been attending the sessions for the past eight months. Charles *'needs one-to-one* support' and Martha was initially concerned about *'not being with him in the water'…* and whether *'there are enough staff around'…* Martha aims to bring Charles to the sessions every week but '*sometimes can't get him motivated enough… to bring him out… or, he's just in his chair, and I can't get him out, you know, because of the Parkinson's… so, we've probably missed about five [sessions] all in total'.*

Charles's attendance and participation is entirely dependent on Martha *'he can't do nothing for himself. So when we come into the changing room, I strip him down, change him, transfer him from his own wheelchair into the hoist wheelchair'.* The centre's large accessible changing room is well equipped with a hoist, bed and hoist chair. Martha considers this plus the overall accessibility of the centre, ease of parking, signage and attitude and ability of centre staff to be key to a positive user experience. She feels that the experience has got better over time and that participants and centre staff have been on a journey together, she describes that at the beginning the staff were *'very tense with him… You know, they've had all the courses, they've had all the training, it's the hands on, it's the practical side… it was a learning curve for them, but there was one particular* [staff] *member… who was used to it. And her experience filtered right down and everyone's confidence just grew, it's really good. I can leave him with anyone now, whereas before, no, no, no, no… Every type of dementia's different. You know, and they need to be adaptable…that's what we found'.* Martha feels that the only areas that could possibly be improved are staff numbers to enable more 1:1 support and the noise in the pool hall, which can be off putting during the school holidays.

When asked about the programme benefits, Martha commented *'it's a full time occupation looking after somebody with dementia. I don't get any breaks'.* However, she feels that both she and Charles have benefitted greatly from attending the sessions, they have met new people in the same position and made new friends who they now see at other activities. Whilst Martha doesn't swim, she feels she benefits altruistically, from seeing the pleasure and benefits that Charles gets from the sessions. She has noticed a difference in Charles's wellbeing, in particular his movement, confidence and mood. It has taken time but Charles's strength has improved as a result of the programme. He can now stand when Martha dresses him and once in the pool he is mobile without assistance, he walks up and down doing breaststroke arms and enjoys swimming underwater. '*The progress is his disability of movement, it's not as blocked as it used to be and I think it's down to this… the deterioration is slowing.'* Charles *'would not eat outside* [the house]*, because he was aware he's a messy eater now. And he can't use a fork and*

spoon properly, and he uses his fingers. He won't eat anywhere else but here… He feels that comfortable... if he wasn't confident, he wouldn't eat'. Charles can be *'a bit grumpy… before a swim, sometimes… but, once he gets there he absolutely loves the one-to-one attention. He jokes in there and just to see him do that, it's absolutely wonderful… It's the knowledge that he can do it* [swim and walk] *on his own as well, you know'.*

Martha's view on encouraging more people to attend the sessions is to *'just publicise it, they've done the leaflets, there's word of mouth, just go out and tell everyone about it.'*

2. Benefits to leisure operators

The evaluation has revealed the benefits to operators from the end-of-project scheme reports, from feedback through our regular meetings with coordinators but also from end-of-project interviews with 22 operators distributed across the country. Operators have told the evaluation team that the availability of DFS funding was the main stimulus for their initial involvement. However, as the programme has grown, there has been a strongly positive feeling about DFS despite the recognised challenges and extra work involved that is necessary to make the programme viable and successful.

It is notable that this support has consistently been seen at the highest levels of management. This is quite surprising given the current general climate of austerity and pressures placed on leisure services to be commercially profitable. For the operators to perceive benefits is essential if the DFS programme is to receive their support over the longer term. This is particularly important as no centres reported an increase in membership (main source of income) as a result of DFS so there is no evidence of economic benefit.

Frequently listed benefits include:

- Bringing new types of customers with different needs has widened perspectives of staff, made them more aware of dementia and improved service. On the whole DFS has been wholeheartedly embraced by them as has been seen in uptake of DFS training. It has helped staff feel more comfortable with people with disabilities and convinced them of the need to ask questions and be approachable.
- Changes in signage, route way markings, and more careful consideration of social areas have been beneficial for all customers but particularly those with health needs. Greater clarity has resulted in fewer queries among customers reducing demands on staff time.
- Some centres have been alerted to their importance as a social venue and as such have developed new policies to upgrade their catering and increase use of their social spaces.
- DFS helps leisure services fulfil their duties to community welfare, which for leisure trusts is a clear part of their charter.
- Increased awareness of the need for and expertise in outreach and this has resulted in the development of rewarding partnerships with other organisations, created a better understanding of community needs, and opened up other possibilities.
- Insight from DFS can be used to inform future commissioning priorities and carry learning into future projects.
- In some cases DFS has helped leisure services raise their profile within Public Health and Social Care.

Comments from end-of-project interviews with leisure operators:

"*It was an opportunity to enhance our program and our facilities, offer even more and help the local community as part of our community development plan*."

"I'm hoping that it will have started us on a pathway of better customer service training and that we can embed the dementia friendly training into our company so that we can actually say that we're a dementia friendly organisation."

"We've got a Dementia Officer now…she's based at the centre and goes out into the community centre to do seated exercises with groups."

"(The programme has enabled us) to reach a wider audience in the local community, bring people into the centre that have not necessarily been to a leisure centre before or thought of the need to come to the centre. I think it's helped us create a more diverse pool programme."

"*I think the whole organization, including senior management, have said it's a great program to be involved with, and there's no reservations, other than just making sure we've got sustainability for the future*."

"*This was sort of an ideal opportunity for us to try something different in terms of attracting different groups to the facilities*."

"*On a Wednesday, you can see probably 20 people all around a table, having a cup of tea, sharing stories, sharing experiences, just chatting with each other, really. That's been great. I think the buy-in from our own staff who have got to know the customers, makes people feel welcome*."

"Centres are really buying into the programme. We have made new partners who wouldn't necessarily have previously worked with us. It has helped promote other older people's activities, e.g. user groups have come to use the centre on other days aside from the swimming sessions."

Perhaps the overall significance of these changes in culture, improvements in skill sets, facilities, outreach and partnership working is that it has paved the way for better provision for people with particular health and social needs who would previously have found experiences in leisure centres too demanding for them. This is important, as in that future customers will be older, have poorer function, be less athletic than they are currently and they are more likely to have additional health needs. In the process, in some cases such as the Bristol scheme it is clear that DFS has helped leisure services raise their profile and engendered trust in local care commissioning groups about their capacity and value in promoting wider health and social outcomes. This is a potential and necessary gain for all leisure providers interested in offering more comprehensive services for the broader community.

4. Benefits to partner organisations

Partner organisations have also experienced additional benefits from participating in the DFS project. Continuum conducted unintended consequences surveys with partners working with a DFS scheme during the second year of the project and again at the end of the project (data not yet available). These partners were involved in advisory groups or working to assist outreach and

recruitment of PwD. The first survey included six Local Authority representatives from outside sport or leisure services, seven from health organisations such as CCGs or dementia friendly alliances, five from charities such as the Alzheimer's Society and Age UK, and one advisory board volunteer.

Many partners reacted with surprise at how well run and well-received their DFS scheme seemed to be. The majority felt that the programme had already made a positive impact.

Frequently mentioned benefits of working with DFS, many of which were integral to their organisation's mission were:

- New and stronger partnerships have been forged as a result of the programme, for example with local Dementia service providers.
- The programme has already and is likely to increase the investment and resources available to run Dementia Friendly Programmes in each local area.
- A belief among the majority that Dementia Friendly Swimming will increase the likelihood of physical activity interventions being commissioned in the future.
- Increasing the profile and strategic importance of dementia locally.
- Provided a new element of implementation of local Dementia Strategy.
- Creating a new work force of Dementia Friendly trained staff.
- Contributing to removing the stigma and barriers associated with dementia in the local community.
- Improved information sharing and collaborative working between organisations.

Comments from partners

"*When this project was introduced I thought that it seemed very ambitious and made the assumption that people with dementia want to go swimming. However, although it has been hard work to recruit people, those who have attended have reaped huge benefits, as well as being more relaxed in the pool it seems to help with frustration and anxiety in daily living. It's a very moving experience seeing someone barely able to communicate and unable to stand, laughing, kicking and splashing once they get in the pool. It has generated a culture change and we are just (Oct 17) seeing an increasing trend upwards in the number of PwD going swimming.*" **(Health Improvement Manager)**

"The staff involved have a good understanding of how much a person with dementia may find a leisure centre a challenging place to be. There has been lots of thought put into the persons experience of attending a session, which I believe is a strength of the programme." **(Manager of Dementia Wellbeing Service)**

"*We have been going for four weeks now and taken nine nursing home residents and have been so amazed at how well it has been organised and how well the people living at Deerhurst respond to going. I can't recommend it enough as the outcomes have been incredible so please pass this on to staff, carers, family members and anyone who you know enjoyed swimming but gave it up when their illness made it more difficult."* **(Care Home Manager)**

There is an appreciation of how links have been strengthened with leisure services and in many cases Dementia Friendly Swimming appears to have raised their status among other partners:

"It has strengthened the partnership in our own village between the nursing home and the community living." **(St. Monicas Trust, Bristol)**

"*We are trying to become a dementia friendly town and this programme is part of that*." **(representative of Dementia Friendly Alliance)**

"The fact that the local authority is exploring this is great and will raise the profile (of dementia) in the community as well as the Council." **(local authority member of DFS board)**

"Our Regional Manager for Bristol, is aware of this fantastic initiative and regularly mentions it to people." **(representative of Alive)**

"This is a new area of commissioning… We are very interested in monitoring the outcomes… to inform future commissioning. We have already started to develop new services with physical activity interventions…" **(CCG representative)**

"The dementia friendly swimming project is a very valuable option for us in Bristol, it contributes to the dementia friendly community model and allows us to be more person centred when working with people with dementia. Our team of navigators and community development co-ordinators within the dementia wellbeing service have seen the value of leisure activities that contribute towards a persons identity and wellbeing". **(Worker, Dementia Wellbeing Service)**

Recognition of DFS and individual schemes

In addition to the benefits listed above, some of the schemes have gained wider recognition:

Nationally:

- DFS was a finalist in the Best Dementia Friendly Project category at the National Dementia Friendly Awards (2015) run by the Alzheimer's Society.
- DFS is mentioned in the Government Sport Strategy, S*porting Future: A New Strategy for an Active Nation*, and as a case study in the Annual Alzheimer's Society Report 2015.
- DFS was showcased through a presentation at the UK Public Health Conference held at Warwick University in September 2015.

Locally:

- Manchester's Project Steering Group won the Best Partnership Award at the Spirit of Manchester Awards in October 2015.
- The Project featured in a video created for the Dementia Pilot project being delivered as part of Greater Manchester Devolution which launches in April 2016.
- The Minister for Sport was present at the launch event for GLL's Hackney scheme which is supported the Chair of the local Health and Wellbeing Board.
- The Durham scheme was nominated and came second and was highly commended in the Durham County Council annual Great Staff, Great Stuff Awards. The project came in second place and was highly commended.
- Two Dementia Friendly Swimming participants were recognised for their achievements at the 2016 County Durham Sport and Physical Activity Awards. They came first place in the Physical Activity Achievement of the year category in the Durham Dales locality awards and were successful in winning the overall county award in the same category.

Section D: Taking Dementia Friendly Swimming into the future

1. Choosing a model of delivery

From the start, an underpinning principle of DFS was to allow flexibility of delivery at local level. This is because of the reality of great variation among local authorities in availability and suitability of facilities, administrative systems, and available resources. This freedom has produced a wide array of models of delivery, each presumably chosen as best to meet local needs and constraints. Roughly they can be differentiated on several dimensions:

i. **Management:** Although most schemes have originated through leisure services, we have three or four examples of schemes which have instead been driven by local dementia services or charities. For example, the Lincoln scheme is led by the local branch of the Alzheimer's Society, the Crawley scheme by the local dementia alliance, and the Bristol scheme by public health in collaboration with leisure services. Schemes managed from outside leisure services have stronger connections with PwD and seem to find recruitment easier. They also have existing experience with PwD and understand their needs. In contrast leisure services know the pool and leisure centre environment well but have to upskill staff and work hard to develop their outreach and partnership work. There are advantages to both models and ultimately the collaboration of both leisure and non-leisure partners are needed for a scheme to work.

ii. **Scale:** The simplest form of delivery, as in the Swim North East scheme, is a single session per week offered in one pool. This has the advantage of being manageable, providing a forum for learning, and a template for expansion. The most complex form of delivery is to offer sessions in several venues. In the Bristol scheme, this has grown to involve large sectors of the city. In the case of GLL, one of the largest leisure providers, DFS has resulted in dementia provision being a general policy for all of their facilities which are distributed across the country. Multiple site delivery in an area has economic benefits in that publicity can be combined and the effects of partnerships for recruitment and expert support can be maximised. Ultimately it is clear that there are economic advantages of scale although these complex models take time to build up. Experience to date suggests at least 12 months are needed.

iii. **Exclusivity of sessions:** Three types of sessions have emerged:

- ***Integrated sessions*** – where a leisure centre has identified a quiet slot in the existing pool programme where one or two lanes can be roped off and used for participants in the DFS programme.
- ***Inclusive sessions*** – where the operator identified and advertised specific open sessions which were quiet and appropriate for PwD but also open to the general public. There will be dementia-trained lifeguard for those sessions, the centre is dementia friendly and people living with dementia can feel comfortable attending a public session.
- ***Exclusive sessions*** – where the operator has designated a specific time slot in a pool (which is usually a training pool or a section of the main pool) dedicated to people living with dementia.

At the start of the project, exclusivity was the favoured approach and still is maintained at least in part in some schemes such as Manchester. However, integration is becoming more

favoured, particularly where sessions are opened up to other groups that may include people with other mental challenges or health needs. This makes economic sense and also fits with a general movement to try to engage people with dementia into more diverse groups of adults and closer to mainstream provision.

iv. **Activity in sessions:** Several schemes offered dedicated aquatics session that often combined arange of activities including free time, games, aqua-relax, and aquaerobics. These were usually led by a swim teacher often with volunteers or carers in the water with PwD and a flexible non-pressured approach applies. These were particularly suitable for PwD who lack confidence or do not swim well. A more common offering was to cordon off one or two swimming lanes during general swimming sessions. Time in the pool was generally 30 to 45 minutes and the amount of activity in terms of energy expended and intensity (METs) is very variable with some people simply enjoying the water experience and freedom it offers while others walk, use floatation devices, and some engage in more concerted efforts to improve their swimming and swim lengths. Some pools provide older style music during the session. Life guards were dementia trained but otherwise sessions were not necessarily led by a swim teacher. The lane sessions have proved popular for those PwD who are confident swimmers and they are cheaper to deliver. Some schemes offered combinations of these different types of sessions for example Crawley encouraged PwD to take part in wider activities available at K2 Crawley, including bowls, health walks and gym membership.

v. **Swimming only or as part of a wider scheme:** For stand-alone swimming pools the activity was usually restricted to swimming or other forms of water-based exercise. However, where pools are part of leisure complexes, there was scope to incorporate DFS into multi-activity provision where there were options of lots of types of activities. This was the model developed in Crawley and several other schemes are moving in this direction. The advantage is the potential for the greater choice to attract more PwD during specific time slots. It means that staff and communication can be very tuned in to customers' specific needs, prepare the centre with extra signage, and volunteers. It may provide a more social and vibrant experience both within and following sessions. Increased numbers would then result in greater cost-effectiveness and sustainability.

At this point, it is not possible to identify an ideal model of delivery. There is no financial evidence on the cost effectiveness of specific approaches. Given that this report has established many DFS participants have low confidence and limited recent swimming experience, it seems that starter dedicated sessions are very important. DFS resources provide guidance and scheme reports as exemplars of approaches for new schemes to consider. Scheme coordinators must choose the most appropriate starting model for their local conditions and needs. However, over the last two years of the project conversations at coordinators meetings have provided greater support for moving towards a more scaled up and inclusive model of delivery.

Multiple activity choices not just for PwD but for people with other health conditions that are held at specific times of the week (usually late mornings or early afternoons) seems to be the *all singing and dancing* model of delivery. This model is gaining support but may only be appropriate for larger leisure centres that include a swimming facility. It has the potential to gain from joint publicity and stronger recruitment which in turn would enhance chances of sustainability. It is clear that DFS has playing a vital role in moving providers to this point in their thinking and provision.

Feedback regarding future scheme development

"It would be good to develop sessions that cater for a range of long term conditions (with appropriate risk assessments), rather than trying to design specific sessions for different illnesses (which isn't really sustainable in the long term), we tried to do this through accessible swims and exercise on referral, but staff were resistant. Perhaps Swim England could support this?" **(Scheme coordinator)**

"For Swim England to explore options of providing a similar project to people with a wider range of long term health conditions. Participants in the dementia friendly swimming project gained a number of health benefits and a similar project developed for people with a wider range of health conditions has the potential to reach more people and improved the health and wellbeing of even more individuals". **(Scheme coordinator)**

2. Costs and sustainability

The current economic climate means that leisure and swimming services are facing reductions in financial support from local authorities. Often leisure contracts are awarded based on the largest potential financial gains and wider outcomes may be secondary. Although leisure trusts have a clear mission to support the health and welfare of the local community, this is becoming increasingly difficult to achieve as they are challenged with the need to create income. This is usually addressed through membership sales, charges for sessions, and additional income from catering. This means that activities and sessions that attract larger numbers and are not expensive to deliver tend to be favoured.

DFS has been relatively costly to deliver in Years 1 and 2, with the main items being:

- Salary for a scheme coordinator (usually part time).
- Training of staff.
- Modifications to facilities such as improved signage and changing room systems.
- Dedicated pool time (costs limited by choosing time in low demand).
- Employment of swim instructors.
- Publicity and marketing.
- Setting up partnerships and recruitment and outreach (usually scheme coordinator).

Starting any new scheme is resource demanding. Schemes have estimated that four to six months are required to prepare venues and establish sufficient recruitees to start a viable programme. Overall the larger schemes have reported total costs for setting up and delivering DFS in the region of £50,000. The largest item has been employment of a scheme coordinator (50-60 per cent) which has been funded through Department of Health funding. This has been needed to manage monitoring and evaluation of the research aspects of the programme, providing reports, attending Swim England meetings, setting up advisory groups, and most of all for building recruitment through outreach and partnership working.

Looking forwards, some of these time consuming elements will be removed once Swim England's engagement and the research element are reduced or removed. However, it is difficult to see how schemes will achieve successful starts without the drive and time of a scheme coordinator. The degree to which these posts will continue to be supported by leisure services and charities remains to be seen. In Lincolnshire this co-ordination role has been picked up by the County Sport

Partnership (CSP). The CSP would be ideally placed to support other projects across England as they have a good understanding of Sport Development and links with wider local partners.

Charging to offset costs has been seen as one method of mitigating cost in some schemes. For example, Swim North East have charged £5 per session. These schemes have provided sessions at the normal rate for swimming and some have offered a concessionary rate (range = free to £5.90). Several schemes have issued no charge at least in the early stages in order to encourage recruitment. Significantly, no operators felt that charges had presented a barrier for participants. Some scheme coordinators also reported that they have benefitted from an upturn in use of cafes at normally quiet times. There is therefore potential to recoup at least some of the cost. However, the reality seems to be that offering a dedicated DFS scheme is more likely to be a loss leader rather than a profit maker for leisure services at least in the early stages. Support may be needed from other sources such as CCGs and charities.

It is indicative of the support and belief in the value of DFS that there remains a good deal of determination by swimming and leisure services to continue with DFS and some schemes seem to be achieving some success. The majority feel sure that funding is secure to keep the project going as part of wider inclusion sessions on an ongoing basis. For example, **Manchester City Council** have committed to continue to support DFS in their pools past October 2017, with a vision to using the learning from the scheme to develop greater support for people living with other long term health conditions. Dementia Champions have been identified to promote schemes in each pool. A Dementia Champion has knowledge and skills in the care of people with dementia. They are an advocate for people with dementia and a source of information and support for co-workers. They will have an understanding of the change process from a theoretical and practical perspective.

In **Lincoln**, although DFS costs were offset by funds from the Mental Health Foundation, each of the three leisure centres have taken the decision to continue with their groups over the next year. Durham will focus on sustaining DFS at only one of their pools. **GLL**, who have many facilities around England, have developed policy to support dementia friendly provision across their centres. The **Crawley Dementia Alliance** have contributed £10,000 to extend DFS for an additional six months as it is now part of a broader range of activity provision for PWD. The **Bristol** team is also in the process of securing the future of their city wide scheme. Many operators envisage future provision that builds on dementia friendly provision but includes a wider range of people with other health conditions. It was suggested by one operator that *Dementia Friendly Swimming* is more likely to be supported and promoted as *Supported Swimming* or something similar.

Scheme coordinators have offered some suggestions as to how Swim England might assist with the long term future of DFS. Staff turnover in leisure services is high and online CPDs for swimming teachers and other key front line professionals, much like they provide for those working with deaf or visually impaired people. Another suggestion is to continue to build supportive central resources for newly developing schemes.

The conclusion is that as leisure services come under more pressure to be self-funding, programmes such as DFS that are cost intensive to deliver, at least in the early stages, are likely to remain vulnerable. This is disappointing because the potential for long term costs savings in reducing the reliance of health needy groups such as PwD on primary and secondary health care and social care services is profound.

Health economics

Very few public health interventions, particularly those that address lifestyles, have robust data on cost effectiveness and economic benefits for health and social care. Swim England engaged the University of East Anglia to assess economic outcomes in terms of measured quality of life for both PwD and their carers across the time span of the Year 2 schemes. Unfortunately difficulties and delays with establishing ethics approval for the project and unforeseen administrative complications and costs that the final approval entailed meant a reappraisal was needed. This was coupled with lower numbers of recruited PwD in the early stages than original expected. The two combined meant that the completion of this research became untenable.

After agreeing that attempting to proceed with individual-level data collect would be unfeasible, a modelling approach was used to estimate the economic impact of the DFS programme. The evaluation was conducted using the Model for Estimating the Outcomes and Values in the Economics of Sport (MOVES v2) model previously developed for Sport England. The model is an epidemiological tool that compares cohorts engaging in a physical activity programme with identical hypothetical cohorts who do not take engage in activity. The model converts physical activity into metabolic equivalents (METS) which can be linked to an expected reduction in the risk of selected diseases, including Type-2 diabetes, coronary heart disease, cerebrovascular disease, breast cancer, colorectal cancer, dementia, depression and hip fracture.

The model is based on a dose-response relationship where programmes that generate more METS, either through greater intensity (i.e. running vs. walking) or greater duration (one hour vs. two hours of activity) lead to a greater reduction in the incidence of disease. This relationship is curvilinear, with smaller marginal benefits associated with changes in METS at the very low and very high end of the scale and greater marginal benefits in the moderate range. The reduction in the incidence of disease is translated into quality-of-life and monetary impacts on the basis of age and sex specific rates, from the perspective of the NHS.

Outcomes in the model include expected costs and expected quality-adjusted life years (QALYs). A reduced incidence of disease due to physical activity results in costs avoided and QALYs gained relative to the hypothetical control cohort. As participants in the DFS programme already have dementia, this condition was excluded from the analysis (i.e. it cannot be prevented by increased activity).

The number of participants and changes in activity levels were based on the DFS tracker forms completed at registration and at 6 months, categorised by sex and age group. Initial activity levels were based on reported baseline activity levels and DFS activity levels assumed participants added one 1-hour leisure swimming session per week (4 METs per hour) to their initial activity levels. The model conservatively assumed that the median participant maintained this activity level for one year. The model assumes the benefits of physical activity on the incidence of disease disappear following drop-out.

The model predicted average NHS savings of £51 per participant and a small QALY gain, primarily through the prevention of hip fracture. Prevention of coronary heart disease was also an important contributor to benefit. This compared to an average operating cost of £36 per participant, including annual DFS coordinator salaries and hourly wages for two lifeguards for one 1-hour DFS session per week over the average of participation (two years based on median of one year participation with 50 per cent dropout per year thereafter). The return on investment to the NHS was estimated to be £1.42 per £1 invested, or 42 per cent. If one assumes that carers participated at the same intensity

and duration as persons with dementia, and derived the same protective benefits from swimming, the return on investment increases to £2.19 per £1 invested, or 119 per cent.

There are a number of limitations to the model. First, it is based on prevention over a lifetime horizon and does not adjust for the prevalence of conditions in different age groups. It assumes that cohorts are disease-free at the beginning of the model and it will overstate the potential benefits of activity and prevention if populations already have a number of prevalent conditions. Second, it is based on age and sex-specific incidence rates in the general UK population, but it is not clear that the risk in the population of persons with dementia will be similar to the broader population. If the risk of the non-dementia conditions included in the model are higher or lower then estimates of benefit will be corresponding under or over-stated. Finally, the model does not account for any improvements in quality of life that may be associated with physical activity following onset of a condition, especially in terms of the social and mental wellbeing aspects highlighted throughout this report. In this respect, the model is a conservative estimate of the benefits of swimming.

3. Key achievements of the Dementia Friendly Swimming Project

The Dementia Friendly Swimming Project has been pioneering work for Swim England. Stimulating long term changes in the way service delivery systems operate is known to be difficult and Swim England is proud that the overall aim of changing practice in swimming facilities to produce rewarding experiences for people with dementia and their carers is being achieved.

Following the Three Frontiers model, there is compelling evidence that where DFS has been operating there has been a substantial improvement in the aquatic experience offered to PwD and their carers. This is substantiated by:

i. **Large numbers of pool and leisure centre staff voluntarily trained** to provide improved service that is sensitive to the needs of PwD. DFS has increased the number of Dementia Friends by 1,467 and the figure continues to grow. Leisure managers are convinced that this has improved staff communication and understanding beyond PwD to other health needy, disabled, or non-sporty groups.

ii. Conversion of our ongoing research findings into a **bank of support tools and materials** that continue to be available to help new scheme coordinators.

iii. Stimulating (in most cases for the first time) **strong partnership working** between leisure services and dementia support services and other charitable and health services working with inactive populations.

iv. Leisure and pool operators **developing their outreach strategies** in order to establish recruitment links with a harder-to-reach population. A major rethink in the way programmes are marketed and publicised has taken place.

v. **Evidence of a two-way benefit with CCG, care organisations and charitable trusts** indicating that they are now better equipped to work with leisure services and in many cases leisure services are more highly valued and trusted suggesting a greater willingness to work on future collaborations.

DFS has broken new ground by providing leisure services with an evidence-based template or exemplar that allows them to become more pro-active and successful in provision for people with long-term health conditions. Taking the broader perspective, the DFS project has acted as a unique

catalyst for a culture shift that has been required to align leisure and community services much more closely with local health plans and with public health as a whole.

Testimony needs to be paid to the efforts of scheme coordinators. DFS has and remains a challenge project. Their dedication and resilience has been a critical element of the success that has been achieved. Even though recruitment of PwD to Dementia Friendly Swimming has been challenging, there have been many encouraging successes. These are evidenced by:

i. A total number of 866 people with dementia and their carers participating with a Dementia Friendly Swimming scheme.

ii. 102 Dementia Friendly Swimming sites and another 18 sites expressed an interest but not gone any further so far.

iii. Limited quantitative and substantial qualitative evidence that people with dementia and their carers are experiencing life enhancing benefits from participation in Dementia Friendly Swimming. These include physical benefits such as reduced pain and improved fitness and balance but these are outweighed by substantial benefits to both psychological and social well-being. For some participants it is clear that Dementia Friendly Swimming has made a huge difference to their quality of life and built up confidence to take on other challenges.

iv. Year 3 data indicating that Dementia Friendly Swimming has stimulated extension of provision to other healthy needy groups so that a further 745 people are also benefitting.

v. Dementia Friendly Swimming has contributed to an increased local and regional awareness and understanding regarding dementia and the challenges it brings.

An accelerating pattern of growth has been witnessed over the three years of the project as highlighted in Table 3. The learning and experience gained by operators and partners seems to have created an enthusiasm for this area of work. The creation of this level of motivation and dedicated bodes well for the future.

4. Swim England's future plans

Swim England will seek to spread the findings of this evaluation alongside all the tools developed more widely through promotion of the website, giving presentations at relevant conferences and delivering a seminar to share the findings.

Swim England has taken on board the findings of DFS, the recommendations of operators and the review of Swim England insight data and has subsequently been in discussions with Sport England about continuation of the project and what is needed to create a sustainable model of delivery.

It is clear from the evaluation that the principle of using the Three Frontiers model to create a whole pool approach to supporting people with dementia has created a cultural change in pools by:

- strengthening partnerships to support recruitment
- making environmental changes
- ensuring staff have a greater understanding of clients' needs
- creating sympathetic pool programmes.

While the focus has been on people with dementia, due to the mixed condition sessions being increasingly delivered in the final year of the project, there has been a wider reach that has included other health needy groups. Ongoing discussions with operators and DFS scheme coordinators have revealed their growing preference for this approach as it makes the programme more sustainable. This is also supported by the conclusions of Swim England's evidence review *The Health Benefits and Wellbeing of Swimming* (June 2017). The report, infographics and response documents can be found at www.swimming.org/swimengland/health-and-wellbeing-benefits-of-swimming

Key findings in the Health and Wellbeing Benefits of Swimming:

- Swimming is associated with reduced morbidity and risk of death due to heart disease (one study predicts this to be 28 per cent and 41 per cent respectively).
- The properties of water make it a conducive environment for exercise enabling participants to meet the aerobic, strength and balance components of the CMO physical activity guidelines for health.
- Swimming and wider aquatic activity is particularly conducive environment for people with long term conditions to exercise and those who may struggle to be active on dry land. This is because the buoyancy puts less stress on joints, the cooling effects of water makes it ideal for people who may overheat on land e.g. people with obesity or pregnant women, and it is a safe and effective environment for people at risk of fall to work on balance and strength.
- The pressure of the water on the thorax and makes it a great environment for people with lung conditions to train respiratory muscles.
- Swimming can support cognitive development, particularly in children and older people and can support positive mental health due to its role in providing socialising opportunities, and rekindling positive memories and providing opportunities for relaxation for people with dementia.
- In addition to the above effects there is also evidence of the positive effects of swimming and wider aquatic activity on cardiovascular and diabetic risk factors, neurological conditions, breast cancer symptoms associated with treatment and cancer related fatigue, mobility for people with Multiple Sclerosis, Parkinson's Disease and stroke and balance and fatigue for people with Multiple Sclerosis.

Every month Swim England undertakes a survey of 1,000 people aged 11+ to improve its understanding of their needs and behaviours in relation to swimming. An analysis of the data from the sector of individuals reporting long term health condition has shown that there is an unmet demand for swimming (23 per cent of those who have a long term condition).

This is particularly the case for people with muscular skeletal conditions (29 per cent) and mental health 21 per cent having an interest in swimming, but may not be engaged because of a lack of awareness and understanding of the benefits relating to their health condition coupled with poor confidence in the water and perceived low swimming ability.

Swim England has also been developing training for exercise referral instructors to develop an aquatic offer to participants. Work is also being undertaken to develop materials for learn to swim instructors on health conditions. This work will support a tailored menu of opportunities for people with a range of health conditions, building on the extensive learning achieved from the Dementia Friendly Swimming Project.

The expanded project will include the following elements:

- Work with long term condition charities to get targeted messaging for people with a range of long term conditions.
- Expanding the dementia friendly swimming training and environmental check list to ensure it encompasses a range of conditions.
- Rolling out of the new Aquatic Activity for Health Qualification to support the development of aquatic exercise referral schemes for people with a number of conditions including dementia.
- Continuing to work with both third sector and health professional bodies to increase recruitment to pools.
- Creating materials and technology to provide a range of options such as learn to swim, exercise referral and supported exercise classes.
- Expanding the dementia friendly swimming brand to ensure it is associated with a trusted and consistent aquatic activity offer for people with long term conditions.

A core element of this work will be to produce a model of delivery that is sustainable and potentially cost effective, showing clear health benefits and helping operators meet contract requirements.

It is envisaged that Swim England will work with the existing Dementia Friendly Pools to develop the model and test the wider scope to ensure it is feasible and sustainable and then seek to roll it out more widely in April 2019 and with a potential reach of over 2,780 public pools this initiative has every chance of making a significant and lasting contribution to the health of the nation by reducing inactivity and supporting people with or at risk of long term conditions.

In 2017, Swim England commissioned major new research into the health benefits of swimming. You can read the full Health and Wellbeing Benefits of Swimming report online at www.swimming.org/swimengland/health-and-wellbeing-benefits-of-swimming

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Figure 14: Project coordinators from across Year 1 and 2 sites

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