

Final Evaluation Report

Age Scotland's Dementia Aware Training Intervention Programme



September 2018
by
Impact Generation

“Since the training, I always use people’s [that I encounter who have dementia] names. I’m kinder and acknowledge that they are there. I don’t think I did that before”

Social Housing tenant and recipient of Age Scotland Dementia awareness training



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EXECUTIVE SUMMARY

1.0 WHAT THIS REPORT IS ABOUT

Age Scotland is a charity that is inspiring the public to see that older people (those aged 50+) and their carers can change their own and others' later life for the better, enabling people to make those changes and supporting those who are struggling to achieve better, happier, healthier lives¹.

To evaluate Age Scotland's dementia aware programme of workshops (2015-2018), Impact Generation was appointed in May 2016 to conduct an evaluation for up to two years.

Age Scotland's dementia awareness programme supports employers, volunteers, carers and individuals in workplaces as well as older people who attend Age Scotland's Member Groups (rural and urban) to increase their awareness levels about early-stage dementia so as they might better interact and/or support them in future.

This report details the evaluation findings collected from August 2016 to April 2018 about the training interventions in this programme. It is appended with ANNEX I that features findings of the face to face surveys undertaken with Trade Union representatives, ANNEX II that details the Research Design and Models, ANNEX III Post-evaluation Survey Results for Employer/Workforce Training and ANNEX IV Grid Analyses of the Qualitative Research Findings.

2.0 EVALUATION RESEARCH CONDUCTED AND NUMBER OF PEOPLE TAKING PART

Both quantitative and qualitative evaluation research was conducted.

a) Quantitative (survey) research method

Two surveys were designed and completed by participants over a 19-month period.

The first, was a baseline (n=495) and post-evaluation (n=121) survey and is referred to as the 'general public' survey. This was completed by attendees of Age Scotland's Dementia Aware Training Programme directly after attending the training session to establish an immediate baseline to track impact and action against. Respondents in this research included those from Age Scotland's Member Groups and employees as well as those caring and/or volunteering with older people. Findings from this survey have a 95% confidence level because of the high response rate in the post-evaluation (21%).

The 'general public survey was designed to explore the impact (if any) arising from the interventions delivered by Age Scotland in personal and social development, capabilities, knowledge and self-care/risk reduction behaviours.

The second survey (baseline (n=159) and post-evaluation (n=11) survey (referred to as the 'Employer/Workplace' survey) was completed by a total of 159 employees in workplace settings at baseline. This survey was also designed to explore the impact (if any) arising from the interventions targeting workplaces and workforce matters.

¹ Age Scotland website, 'who we are', searched July 2017, <http://www.ageuk.org.uk/scotland/about-us/our-work/>

For the workplace, Age Scotland designed two different training interventions. One was aimed at employees in general and the other was specific to HR professionals. Findings from the ‘Workplace/Employer/HR’ survey have less than a 90% confidence level because of the low number of returns in the post-evaluation (6.5%).

b) Qualitative (views and opinion) research methods

Qualitative research was designed and was completed by participants over a 21-month period. Qualitative research (focus groups (n=5) and depth interviews (n=22) took place in 10 different organisations, including, Scottish Prosecution College, Glasgow Film Theatre, Scottish Childrens’ Reporting Administrator, Trust Housing Association, Communication Workers Union (CWU), Unison, Unite, Prospect and GMB.

The focus groups and depth interview research were similarly designed and delivered to determine the differences (if any) made to levels of dementia awareness and to risk reduction behaviours of the people attending the training intervention/s.

c) Recruitment process and respondent profile

Recruitment for the qualitative research was identified by an Age Scotland staff member for budgetary reasons, with Impact Generation’s research team making contact directly with each organisation suggested.

Respondents in both the quantitative and qualitative research included older people (aged between 50-80+), carers, volunteers, Age Scotland employees, managers, HR personnel, middle management and Senior Directors.

Responses to the general public survey (n=495) suggest that nearly 10% of respondents in the survey research were employees who were caring for someone who is experiencing dementia (paid or unpaid).

3.0 KEY FINDINGS SUMMARY

a) General public findings

When asked to describe their level of dementia awareness before the training course, 66% of attendees stated in the general public baseline survey that they were only partially aware of how to interact with someone with dementia. Only 10% described themselves as fully aware.

Findings in the post-evaluation survey (completed at 6-9 months following the intervention) suggest that multiple impacts have resulted. Please note: 92% of the general public survey findings are from Age Scotland Member Groups. Significant findings include:

- Dementia aware knowledge retention is still high and respondents are likely to correctly identify personal risk factors of dementia over the medium to long term. For example, 89% correctly choose smoking as a risk factor in the post-evaluation general public survey (a small decrease of 10% on baseline figure), 97% indicated physical inactivity (increase of 1% on baseline) and 100% cite mental inactivity (increase of 6% on baseline) as risk factors.

- Those who have already attended an Age Scotland dementia aware session (aimed at the general public) have prompted others to attend as they rated the value to them and their family.

- 86% stated that they had spoken more slowly and clearly, repeating back anything when asked to do so when they encountered someone with dementia
- 84.5% indicated that they had remained calm and friendly when speaking to someone with dementia
- 74.5% stated that they had spoken to the person experiencing dementia directly and not to another person / carer accompanying them

- Prevention behaviour/s and activities to lower risk of dementia are being undertaken by a high proportion of attendees. For example, many attendees are increasing personal levels of physical activity, undertaking regular mentally challenging activity (like crosswords, Sudoku, scrabble etc.), increasing social activity and modifying their diet. Many participants have already used the tips and recommendations to support those people who are exhibiting signs and symptoms of dementia on a regular basis.
- Dementia aware behaviour/s towards people with dementia are adjusted. For example, a large proportion (89%) self-reported that they had listened carefully when they encountered someone with dementia, 86% stated that they had spoken more slowly and clearly, repeating back anything when asked to do so; 84.5% indicated that they had remained calm and friendly when speaking to someone with dementia and 74.5% stated that they had spoken to the person experiencing dementia directly and not to another person/carer accompanying them.
- More positive dementia aware behaviour/s were reported to be used regularly by attendees. 36% of respondents stated that they had used the activities and tips said they had done so up to twice a week with 13% stating they used them every day. Less than 17% stated that they used the tips twice a year.
- Dementia aware capabilities in members of the general public following attendance at Age Scotland's dementia aware training had sustained in several ways. On a scale of 1 (low capability) to 7 (very high capability), 49% rated their ability to help someone with dementia to live life well as 5 (increase of 29% on baseline findings), with 19% selecting 4 (increase of 15%).

b) Employer/Workplace findings

At baseline (completed directly after the training took place), when asked to describe their level of dementia awareness before the Employer/Workplace training course, 47% of attendees stated that they were only partially aware of how to interact with someone with dementia. Only 12% described themselves as fully aware.

Findings in the post-evaluation Employer/Workplace survey (completed at 6-9months following the intervention) suggest impacts on employees and their organisations have resulted but there is more to do.

31% of respondents who attended Age Scotland's Employer/Workplace dementia aware training rated it with a 5 out of 7 (7 being the highest) score for having an effect on their organisation. 40% rated the course has being 6 out of 7

Significant findings from Employer/Workplace research include:

- Age Scotland's Employer/Workplace training is likely to make workplaces more dementia aware. For example, 31% of respondents attended the Employer/Workplace training rated it with a 5 out of 7 (7 being the highest) score for making an effect on their organisation with 40% rating the course has being 6 out of 7. Those who have already attended a session have prompted colleagues/others to attend as they view it as a high value activity to undertake (professionally and personally).
- Attendees were motivated to implement a new policy or approach in their organisation following attendance at Age Scotland's Employer/Workplace training. For example, of those who responded in the post-evaluation workplace survey at 3+months (n=11), 28% rated the likelihood of them being able to implement a new dementia aware policy in their organisation with a score of 6 out of 7 on a scale of likelihood to implement (where 7 was the highest score). 14% rated the training as a 5 out of 7 and 14% rated it as a 7 out of 7. 42% of participants rated the likelihood to implement a new dementia aware policy or approach in their organisation as a 4 or less.
- Improvements in an organisation's approach were believed to be more likely as a result of undertaking the training, though a quarter attending were less confident about organisational approaches changing. For example, 26% of attendees rated the likelihood of the training to improve their organisation's approach as 5 out of 7 and 41% of participants rated the improvement of their organisation's approach as a 6 out of 7.
- In some instances, the improvement in knowledge and learning has led to an increased motivation to take action to create more dementia aware workplaces and settings, though this has largely rested upon personal motivation levels of individuals in each organisation to progress. Many participants have already used the tips and recommendations to support those people who are exhibiting signs and symptoms of dementia on a regular basis.
- There are two distinct findings from Trade Unions when compared to the qualitative research findings with employees. Firstly, one distinction was how equality legislation

could be utilised to prioritise the rights of those with a diagnosis of dementia and their carers in the workplace. A second distinction was how participant views centred on lowering the barriers to ‘activate’ those rights as part of a cultural movement, enlisting the help of a senior corporate context.

Views in the research largely centered on the rights of workers to seek and be supported should they start showing early symptoms of dementia but there are wider cultural and resourcing barriers that are still needed to ‘activate’ those rights

- Union representatives interviewed report that during the course of their work where dementia is a factor that a clear gender imbalance exists. According to participants in the research, this imbalance adversely affects women more than men because women are often the main care giver to a person or relative with dementia, the typical person in households in Scotland who has usually made the least pension contributions during the course of their career.

4.0 KEY CONCLUSIONS

a) Conclusions for general public dementia aware training

- Increased awareness, knowledge and capability results from attending Age Scotland’s dementia aware training and results in participants being more able to actively support those with dementia to live life well when the opportunity arises.
- Data gathered suggests that the dementia awareness raising courses are offering detectable outcomes for Members in Age Scotland’s Member Groups particularly to reducing personal risk of getting dementia.
- Carers and/or people with dementia are keen to say in work for as long as possible and needed added support to do so (like understanding support and networks for local carers).
- The general public training intervention works well with Member Groups to improve their dementia awareness levels however awareness and knowledge reduces overtime and because not all people who attend the groups encounter people with dementia so their skills and knowledge are not applied soon enough to ‘trial’.
- Risk reduction information about how to lower risk of getting dementia is a key motivating factor for the general public to undertake preventative measures (like more exercise, more mentally stimulating action like crosswords/card games) on a personal basis.

- Wider members of the public i.e. those who are not attending Age Scotland's Member Groups could benefit from learning about prevention of dementia risks.
- Information packs for Age Scotland's Member Groups have been used to improve dementia awareness levels of members.
- Some reported confusion between dementia and Alzheimer's symptoms and more is needed to distinguish between the two health conditions to improve knowledge and awareness between the two.
- Dementia awareness gained as a result of attending Age Scotland's training intervention helps older carers who have lost someone close to them through dementia make sense of what happened to them and their loved one.
- Dementia awareness improves the 'tools' in a carer's toolbox to better support those with dementia and prompts support seeking from other sources normalising taking action to seek support

b) Conclusions for Employer/Workforce dementia training

- Evidence suggests that because of the high satisfaction ratings for Age Scotland's activities, that matters learned by participants are passed onto others to share in that learning.
- Employers would like more support and would like to understand what fair routes are open to them when handling performance limitations resulting from the impact of dementia on an employee.
- Organisations that proactively seek to include those with dementia aware practices, are more likely to do so when viewing such activities as part of future workforce planning/preparedness and risk reduction practices.
- When leadership of organisations is prepared to take action that there are more follow-up actions and organisational changes planned over the longer term, sustaining change for longer.
- Carers at work and care agency employees are viewed as being pivotal to the quality of life that someone with a diagnosis of dementia has at home and/or the workplace.

5.0 KEY RECOMMENDATIONS

a) Recommendations for general public dementia aware training

- Embark on tailored communications campaigns about how to support people with dementia, tailoring approaches to specific target audiences in Scotland. For example, communications could support carers when caring for a partner/relative at home with dementia how to live life well, smokers and young drinkers about risk prevention and commuters about what to do when you encounter someone with early stage dementia symptoms when travelling.
- Expand access points for Age Scotland's general public training e.g. into community centres, public meetings/community and parish council meetings, leisure centres etc. for members of the public to attend.
- Compose practical guidance for Age Scotland's Member Groups about how to approach and support members exhibiting dementia symptoms and/or diagnoses at differing stages of progression of the condition.
- Member Groups should be encouraged and supported to set-up dementia aware networks and seminars in their local area to cascade knowledge, information, points of contact and support in their areas.
- Ensure that the symptoms of dementia and Alzheimer's are distinguished further in any future training courses aimed at supporting the general public.
- Undertake further research into adverse effects on family relationships when working full-time and part-time whilst also caring for someone with dementia

b) Recommendations for Employer/Workforce dementia training

- Tailoring of the dementia aware training intervention is needed to further support employers to make workplaces more dementia aware and to prompt sustained action within organisations over the medium to longer term.
- Compose practical guidance for employers and managers about how to approach and deal with employee dementia diagnoses in light of equality legislation and workplace instances of dementia and caring for someone with dementia.
- Conduct research into how Unions could work with HR and Senior Management within large workforces to uphold rights-based approaches and dementia aware policies in Scotland's workplaces using collective bargaining approaches rather than voluntarism to make adherence to dementia equality policies more consistent. Examination of how this could be undertaken within equality law compliance within larger public sector workforces under Public Sector Equality Duties should be included.
- Consideration should be made to develop statutory CPD qualification/s for dementia aware training to maintain employee capabilities and level of dementia awareness overtime as well as retain knowledge levels and provide quality assurance. Particular emphasis should be placed on agencies in Scotland that are

supplying contract care staff to those supporting people with a diagnosis of dementia and older people.

- Undertake further research into adverse effects of dementia on women in society should be explored to address inequalities reported by Trade Union representatives.
- Development of tailored dementia aware training to carers and care staff/care supply agencies in workplace settings should be given some consideration. The evaluation evidence suggests that agency supply staff and carers of those with early stage dementia often become informal experts to others who wish to know more about how to reduce their risk and/or how to provide care and are at the sharp end of providing standards and quality of care for those with dementia.
- Consideration of how to improve response rate for any future workplace training survey research should be made.



CHAPTER 1: HOW THIS REPORT IS STRUCTURED

This remaining sections of this Report are sequenced in the following way:

Chapter 2 details participant engagement levels in both the general public and Employer/Workforce surveys, focus groups and depth interviews.

Chapter 3 describes general public findings, covering both general public training focus group and depth interview findings as well as survey findings.

Chapter 4 notes the Employer/Workforce findings, covering both general public training focus group and depth interview findings as well as survey findings.

Chapter 5 summarises analysis and findings about the dementia aware training by participants. It details overall learning from the dementia training by participants, their behaviours and results instigated by the training. It also describes the personal and organisational opportunities reported by participants since attending the dementia training by participants as well as their motivation levels to put the training into practice, covering overall findings from dementia training with Trade Union representatives.

Chapter 6 notes the overall conclusions and impacts resulting from the findings regarding Age Scotland's dementia aware training.

Chapter 7 lists a number of recommendations for future general public and Employer/Workforce dementia aware training.

Chapter 8 details the evaluation team contact details who conducted this study.

Lastly, Chapters 2-7 make reference to four supporting Annexes. These are:

- **Annex I - Trade Union survey research**
- **Annex ii - Research design and models**
- **Annex iii - Post-evaluation survey results for Employer/Workforce training**
- **Annex iv - Analysis grids of all focus group and depth interview research**

Each chapter now follows.

CHAPTER 2: PARTICIPANT ENGAGEMENT IN SURVEYS, FOCUS GROUPS AND DEPTH INTERVIEWS

Chapter content

This chapter gives a full breakdown of the profile and the number of participants that have taken part in the evaluation study as well as describing the approach and methods used in the evaluation. See Annex II separately appended to this Report for more information about how the survey, focus group and depth interview research was designed and which theory of change models were used. Annex II also details the participant recruitment approach.

It is divided into five key sections:

Section 1.0: Participant engagement in surveys details the participant engagement levels in both surveys i.e. for the general public and Employer/Workforce types. It explores the social impact/s arising from awareness-raising activities with respondents in workplaces as well as those participants attending Age Scotland's general public training and other activities from August 2016 - April 2018.

Sections 2.0, 3.0 and 4.0: Participant engagement in focus group and depth interviews details the qualitative research methods used in the evaluation and participant levels. Section B describes the recruitment and research methods for the focus-group and depth interviews that aimed to explore social impacts arising from awareness-raising activities conducted with several types of organisations from April 2017 - April 2018.

Lastly, **Section 5.0** notes about the limitations of the evaluation research methods used. It is best practice in evaluation studies to acknowledge limitations of research methods so as findings are viewed in context.

1.0 PARTICIPANT ENGAGEMENT IN SURVEYS

a) Respondent profile in general public survey at baseline

Respondents completed the general public survey directly after attending the training and answered a total of 16 questions about the effectiveness of Age Scotland's dementia aware training in terms of communication, prevention, behaviours/action, knowledge and practice. 92% of the general public survey findings are from Age Scotland Member Groups.

Participation statistics for general public training survey at baseline include:

- Four hundred and ninety-five (495) participants completed the general public baseline evaluation survey.
- 116 incomplete survey returns (though all 80%+ complete).
- Of the total number of respondents, 34% of respondents to the general public baseline survey indicated that they work with older people.

- 22% were older people aged between 50-80+ and 16% stated that they volunteer with older people.
- 18% offered alternative responses to categorise their profile. This included people who both work and volunteer with older people, including: cancer support officer, a drama therapy coordinator, student, a third sector employee, a Red Cross Project coordinator, a befriender, and housing and healthcare employees.

b) Respondent profile in general public survey in the post evaluation

Respondents completed the general public survey directly after attending the training and answered a total of 16 questions about the effectiveness of Age Scotland’s dementia aware training in terms of communication, prevention, behaviours/action, knowledge and practice. Post-evaluation survey respondents completed an online or paper-based survey within 3-9 months after attending Age Scotland’s dementia aware training.

Participation statistics for general public training post-evaluation survey include:

- 121 participants completed the evaluation survey for general public training.
- 19 incomplete returns (though were 88% complete).
- Post-evaluation findings for general public are based on a 21% response level, answering a total of 16 questions consistent with topics set at baseline.
- Response rate of 20-30% is considered to be highly successful and gives a margin of error for all findings in the survey between 1-5% which can be expressed as a 95% confidence level.
- Of the total number of respondents, 22% of respondents to the post-evaluation survey indicated that they work with older people, 15% were older people aged between 50-80+, 18% were Age Scotland employees, and 17% stated that they volunteer with older people. Seventeen percent offered alternative responses to categorise their profile. This included people who both work and volunteer with older people, including: a retail manager with members of staff aged 60+, work with people who are affected by dementia and ‘scam prevention’ team worker.

Over the next few pages, tables now follow with a full breakdown of the respondent profile in the evaluation.

Table 1.0 shows survey response rate in the evaluation for each type of dementia awareness training activity delivered. Table 2.0 gives a breakdown by respondent type completing the ‘general public’ Survey and Table 3.0 also gives a participant profile completing the Workforce/HR/Employer Survey.

Table 1.0 shows survey response rate in the evaluation for each type of dementia awareness activity delivered

DELIVERED BY AGE SCOTLAND	NUMBER OF BASELINE EVALUATION SURVEYS COMPLETED (FORM A)	NUMBER OF POST-EVALUATION SURVEYS COMPLETED (FORM B)	COMPLETION RATE ONLINE	COMPLETION TIME ONLINE
GENERAL / AGE SCOTLAND MEMBER GROUP AWARENESS BASED ACTIVITIES	495	121	92%	8-mins
PARTICIPANT TOTALS IN EMPLOYER INTERVENTIONS	338		n/a	n/a
EMPLOYER/WORK PLACE BASED AWARENESS ACTIVITIES	159	11	83%	7-mins
PARTICIPANT TOTALS IN GENERAL INTERVENTIONS	1055		n/a	n/a
TOTAL SURVEY RETURNS	654	132	n/a	n/a

Table 2.0 Breakdown by participant type completing the ‘General public’ Surveys

PARTICIPANT DECLARED ROLE IN RELATION TO OLDER PEOPLE AND/OR THOSE AT RISK OF DEMENTIA COMPLETING SURVEY	% OF TOTAL BASELINE SURVEY RESPONDENTS	% OF TOTAL POST-EVAL SURVEY RESPONDENTS
CARER FOR OLDER PERSON AND/OR THOSE WITH DEMENTIA	4.4	3.1
OLDER PERSON AGED 50+	9.5	3.1
OLDER PERSON AGED 60+	7.2	1.6
OLDER PERSON AGED 70+	3.5	6.4
OLDER PERSON AGED 80+	1.2	4.8
WORK WITH OLDER PEOPLE	34.1	22.2
ADVOCATE FOR OLDER PEOPLE	2.2	4.8
AGE SCOTLAND EMPLOYEE	3.6	19
VOLUNTEERS	16.3	17.5
OTHER	18	17.5

Table 3.0 Breakdown by participant type completing the Workforce/HR/Employer Survey

PARTICIPANT DECLARED ROLE IN RELATION TO OLDER PEOPLE AND/OR THOSE AT RISK OF DEMENTIA COMPLETING SURVEY	% OF TOTAL BASELINE SURVEY RESPONDENTS	% OF TOTAL POST-EVAL SURVEY RESPONDENTS
I AM AN EMPLOYEE WORKING EVERYDAY WITH CUSTOMERS/PUBLIC	40.0	43.0
I AM AN EMPLOYEE WORKING AS A MANAGER	24.0	15.0
I AM RESPONSIBLE FOR TRAINING TO SUPPORT OLDER PEOPLE	2.0	14.0
I AM AN HR PROFESSIONAL	16.5	0
I AM RESPONSIBLE FOR IMPLEMENTING POLICIES FOR OLDER PEOPLE IN MY ORGANISATION	2.0	0
I AM EMPLOYED/VOLUNTEER WITH OLDER PEOPLE IN MY SPARE TIME	2.0	0
I AM AN EMPLOYEE WHO CARES FOR SOMEONE EXPERIENCING DEMENTIA	10.0	14.0
I AM A DIRECTOR	3.5	14.0

2.0 PARTICIPANT ENGAGEMENT IN QUALITATIVE RESEARCH

a) Focus group and depth interview research methods

To form an in-depth perspective about the differences (if any) resulting from Age Scotland’s dementia awareness raising training with specific sectors, qualitative research focus groups and 1:2:1 depth interviews were designed and delivered.

See Annex II separately appended to this report for more information about how the focus group and depth interview research was designed and which theory of change models were used. Annex II also details the participant recruitment approach.

All groups and interviews were voice recorded with participant consent gained verbally and in writing via the Housing Association.

b) Engagement level in the evaluation

Two focus groups and several depth interviews were carried out. One focus group was conducted on the premises of Glasgow Film Theatre and the other at the Scottish Prosecution College. This research was conducted at a 3-9month interval following training delivery.

Ten 1:2:1 depth telephone interviews were completed with participants from the Scottish Children’s Reporters Administration (SCRA). It was not possible to conduct focus groups with the participants from SCRA as they were located at local offices across Scotland and their caseload/diaries could not be aligned to allow a physical meeting/focus group to be set-up in the required time-scale. A depth interview was conducted with one participant from the Scottish Prosecution College who was unable to attend the focus group.

Table 4.0 shows the number of focus groups and 1:2:1 depth interviews with Scottish Prosecution College, Glasgow Film Theatre and Scottish Childrens’ Reporting Commissioner

ORGANISATIONS	FOCUS GROUP PARTICIPANT NUMBER	1:2:1 DEPTH INTERVIEWS
GLASGOW FILM THEATRE	6	N/A
SCOTTISH PROSECUTION COLLEGE	4	1 (PERSON UNABLE TO ATTEND GROUP)
SCOTTISH CHILDREN’S REPORTERS ADMIN	N/A	10
TOTAL ENGAGED	10	11

3.0 SPECIAL PROJECT RESEARCH WITH THE TRUST HOUSING ASSOCIATION (THA)

a) Focus group and depth interview research methods

To form an in-depth perspective about the differences (if any) resulting from Age Scotland’s dementia awareness raising training with the Trust Housing Association, qualitative research focus groups and 1:2:1 depth interviews were designed and delivered. This research was conducted at a 3-9 month interval following training intervention delivery.

See Annex II separately appended to this report for more information about how the focus group and depth interview research was designed and which theory of change models were used. Annex II also details the participant recruitment approach.

b) Engagement level in the evaluation qualitative research

The age range of participants (n=25) in the focus groups held with tenants living in Sheltered Housing in Trust Housing Association properties ranged from 56-84. Groups were held in Aidrie and Motherwell.

Four participants had learning difficulties and three had a physical impairment. Two participants disclosed that they were currently caring for someone with dementia. One participant disclosed that they personally believed they were already experiencing dementia symptoms and another disclosed that they had serious mental ill-health. In addition, two depth interviews were also conducted with the Association’s Local managers in both locations.

Disclosure of personal details/health matters by Participant

In both locations, a number of participants in the focus groups disclosed they were either concerned that they were already experiencing early stage dementia and/or needing more information in relation to their own personal circumstances of caring and their own health. In these instances, these disclosures were made known by the interviewer to the Project Lead at Trust Housing Association.

Engagement level in Special Project Research in Trust Housing Association

In total, two depth interviews with Trust Housing Association Project Leads and the equivalent of four focus groups took place with Trust Housing Association. Table 5.0 shown next shows the engagement levels in each qualitative evaluation method in both locations where the research was conducted.

Table 5.0 Shows engagement rate of participants in focus group and depth interview evaluation research with Trust Housing Association

TRUST HOUSING ASSOCIATION (THA)	FOCUS GROUP PARTICIPANT NUMBER	DEPTH INTERVIEWS WITH THA PROJECT LEADS
AIDRIE	9	1
MOTHERWELL	16	1
TOTAL ENGAGED	25	2

4.0 SPECIAL PROJECT RESEARCH WITH TRADE UNIONS IN SCOTLAND

To form an in-depth perspective about the differences (if any) resulting from Age Scotland’s dementia awareness raising training with Trade Union representatives, quantitative and qualitative research was conducted. This consisted of 1:2:1 depth interviews and face to face survey interviews. This research was conducted at a 3-9 month interval following training intervention delivery.

See Annex II separately appended to this report for more information about how the focus group and depth interview research was designed and which theory of change models were used. Annex II also details the participant recruitment approach.

a) Engagement level in the evaluation

Thirty-two face to face survey interviews were conducted directly before and after the training intervention to provide a baseline and immediate gauge of the learning that took place as a result of the intervention. The face to face survey findings are captured in full in Annex I. Annex I is appended to this report. A summary analysis of the depth interview findings is provided in the summary grid analysis.

Then nine depth interviews were conducted with a sample of the same representatives who consented to being re-contacted over the telephone approximately 12-months after receiving the intervention. These interviews intended to provide a gauge of the longer-term impact that the training may have had. A summary of the depth interview findings are featured in this chapter.

Table 6.0 featured on the next page shows engagement rate of participants in depth interviews within the evaluation research with Trade Union representatives in Scotland.

b) Gauging impact using the special project research

The discussion guides used for the Special Research Project with Trade Unions were designed similarly to those designed for Scottish Prosecution College, Glasgow Film Theatre and Scottish Childrens’ Reporting Commissioner.

Table 6.0 shown next engagement rate of participants in focus group and depth interview evaluation research with Trade Unions in Scotland.

Table 6.0 Engagement rate of participants in focus group and depth interview evaluation research with Trade Unions in Scotland

UNION	REGION IN SCOTLAND	NO OF INTERVIEWS
CWU	Shetland	1
UNISON	Dundee	1
UNISON	Dumfries	1
PROSPECT	Glasgow	1
PROSPECT	Edinburgh	1
UNITE	Edinburgh	1
CWU	Glasgow	1
GMB	Edinburgh	1
TOTAL	5	9

5.0 LIMITATIONS OF THE EVALUATION METHODS

Noting the limitations of social research methods in evaluation reports is standard and best practice in research terms. See Annex II

a) Steps taken by the evaluation team to reduce bias in the evaluation study

The social research methods used in this evaluation have used best practice methods to limit any bias in the study. For example, the approach taken has been a ‘mixed method’ i.e. used both quantitative and qualitative methods of data collection. As such, this has allowed cross-referencing or ‘Triangulation’ of the types of quantitative and qualitative data collected in the evaluation. Note: Triangulation processes can help to ensure that findings have a higher reliability and confidence level. Plus, all research has been designed upon validated social science theories of change to reduce bias and aid insight gathering and understanding.

Equally, the researchers who have collected the data have overseen and inputted into the thematic analysis stage in the qualitative research as well as written and reviewed this report for robust process and consistency.

Nonetheless, it is important to recognise that no matter how routinely the research is gathered, studies involving people, especially if they are deemed vulnerable and/or infirm, is intrinsically difficult. It is also important to note that the process of systematically gathering, analysing and interpreting information about the resilience behaviours (the way a person acts, overcomes or reacts to the environments, actions and people around them), knowledge, beliefs, attitudes and values of human populations is not exact.

b) Limitations in this study for readers to note

According to the Social Research Association (2012): *“Social Research cannot normally be reduced to a mechanical formula - good research needs careful craft skills, intelligent creativity in the way they are collected and applied as well as the knowledge and ability to understand the way people think, feel and behave”*. For the Age Scotland evaluation therefore, there are a number of limitations for readers to take note when reading the findings. These include:

- People/members, particularly at an older age, who take part in any social research can be highly complex and some language can also be imprecise. There has therefore been a nominal amount of interpretation taken by researchers to clarify meaning in the context of what has been discussed in focus groups and interview and analysis stage
- Human beliefs, opportunities, capabilities and motivations are hard to exact 100% and ‘pin-down’ and, in some circumstances, have required *a nominal amount of interpretation by researchers when mapping a theory of change* (Social Research Association, 2002)
- Memory and re-call is fallible and participants are not always able or willing to report their feelings or resilience behaviours accurately or honestly even in 1-2-1 and large and small group situations. There is an unconscious social desire - especially in groups where people know each other - to please and agree with others, even if their own views differ from the group consensus

We trust that all findings and analysis in this report will be digested in light of these limitations accordingly.

CHAPTER 3: GENERAL PUBLIC FINDINGS

Background

This Chapter describes the qualitative and survey findings from the general public training.

Improvements in dementia awareness, reducing personal risk of dementia, inclusion of people with dementia, prompting change in organisational care culture for older people and older people's dementia aware needs. These are described in more detail next.

SECTION 1.0 - GENERAL PUBLIC TRAINING FOCUS GROUP AND DEPTH INTERVIEW FINDINGS

a) Improvements in dementia awareness

A number of improvements in knowledge and dementia awareness in older people following attendance at Age Scotland's general public training sessions are also suggested by the research. For example, older people in the research stated:

- *"I would say that I am now partially aware about dementia".*
- *"I think I've got [early stage dementia]. I've got a very poor memory today. It's just getting worse. I can remember the present, but I forget the past".*
- *"Tablets can be taken for dementia. Right?"*
- *"What always sticks with me is the memory loss and what to look out for".*
- *"How much exercise do you need to do to help to prevent it?"*
- *"The session by your lot [Age Scotland] makes you better aware about dealing with other people. I remember it now. It's the different parts of the body it affects".*

"I especially liked learning about the socialising bit. I don't feel as guilty knowing its good for my health and enjoyment levels"

**Older female, Age Scotland
Member Group**

b) Reducing personal risk of dementia

A number of changes in terms of personal action were indicated in the research following attendance at the general public dementia awareness training in older people.

These actions reduced risk of getting dementia to self, to reduce risk for others, to improve observation of signs and symptoms and to use everyday tips to support others who may be experiencing signs of dementia and dementia itself. For example, older people living in sheltered accommodation stated that since attending the training they had:

- *“Been more [social events] on since the training I think. Perhaps it was always on but I didn’t have much motivation to go. Knowing it helps [to lower risk of dementia] does help you go and do it”.*
- *“Yes we now do the Wii Fit. It was added after the training with Age Concern”.*
- *“It’s Games Night on Wednesday but now [because of the dementia aware training] there’s more of a reason to go”.*
- *“On a Thursday night I do arts and crafts. Every Thursday. I make different things like these Paper flowers and Easter baskets. These flowers are made out of toilet roll! [everyone laughs]. But the lessons make me concentrate so hard. I lose track of time. But now I also know that as well as enjoying it, they are doing me some good. To my health I mean”.*

“Eating different foods. You think about a fresh diet to lose weight. Not to reduce risk of dementia and I’ve reduced my smoking a wee bit since the man came along [from Age Scotland]”
Older female, social housing tenant

By far, doing more walking and socialising to prevent dementia was referred to the most by older people. For example, older people living in sheltered accommodation stated that since attending the training they had undertaken:

- *“More with others. Getting a bit more social. It makes you feel like it’s OK just to sit and chat - the fact that it can be good for you is just reassuring. It’s not so much wasted time!”*
- *“[Age Scotland’s session] makes you more aware of what you’re doing to yourself. Most of us have started walking more. I started walking out at lunchtime with these two [pointing at fellow participants]”.*

- *“I’m now doing a local sponsored walk. For four hours! It’s to raise funds for our trip out. We’re doing two this year instead of one”.*
- *“I was always fit and active, but I am definitely doing more now as a result of coming to the last session”.*
- *“People coming in and telling what’s what helps to [prevent dementia] keep you going. You need a kick now and then to keep at it”.*

“[Age Scotland’s session] makes you more aware of what you’re doing to yourself. Most of us have started walking more. I started walking out at lunchtime with these two [pointing at fellow participants]”

Older female

c) Inclusion of people with dementia

Evidence gathered also suggests that older people were prompted to support those with dementia more proactively and were more pre-disposed to change their behaviour towards those with dementia or who may be displaying early signs of the disease. Older people in the research and the local lead in the housing association reported:

- *“You see folk in here and I would help someone in the corridor now. I will use their name. Face them. Be kind”.*
- *“I will show them where to go. To ensure they were comfortable. They can have accidents”.*
- *“I’d like to say that I speak to them normally. Like I speak to others”.*
- *“I’m not sure I’ve ever met someone that far gone”.*
- *“I always use their name too. I’m kind and I acknowledge that they are there. I’m not sure I used to do that”.*
- *“I’ve noticed residents talking differently to those experiencing dementia”.*
- *“I’ve recently been visiting a park that I remember as a child. Just to stimulate fond memories and my mind”.*

- *“People with dementia and symptoms of it, need as much compassion as possible. It’s worse than cancer - there’s treatments for that nowadays. This is really misunderstood and there’s stigma about mental health conditions too”.*
- *“We turn to Sarah (name changed) for help when we need to ask things. I remember asking her about my friend who was in hospital with it because there was no place else for her to go”.*
- *“People have been making more allowances for residents here. You have to understand when people have it and make allowances”.*

“I’ve been more compassionate to one of the residents in here. I now accept that he’s not himself and it’s down to the dementia”

Older female, social housing tenant

d) Prompting change in organisational care culture for older people

Evidence gathered also suggests that changes by organisations that care for older people were also prompted as a result of engaging with Age Scotland’s dementia aware training programme when the leadership in that organisation was being proactive.

Changes that were reported were the purchase of new tools, re-invigoration of the activities timetable to include more dementia aware and prevention activities. For example, older people in the research and the local lead in the housing association reported:

- *“Like the Group said, we’ve got an additional trip planned to help one of the residents to bring back his memory of being a breeder and working on the dog track. He’s got early stage dementia but when anyone talks about it, he lights up. So following the Age Scotland visit, one of the residents said why didn’t we go to the Dog Track. So were off in a couple of weeks. So David (name changed) will be reminded and the others will be promoted to talk to him. A social setting that he recognises should ensure that others can interact with him whilst having fun”.*
- *“You can see we always keep the posters up. Change them when new ones come in”.*
- *“The Trust bought us a dance mat as well. We’ve got arts and craft stalls. The memory games are for everybody too”.*
- *“We’ve been taking small steps and placing some emphasis on getting fit. Walking. Taking more time to chat to others. It’s been paying off. As you can hear!”*

- *“They’ve been doing Wii Fit for a while but the dance mat is new. You’ve got to keep it small at first. Then build up their confidence. The dance mat will improve hand-eye co-ordination and motor skills in general. As well as balance”.*
- *“I look back and think I should have been more understanding with my wife Margaret. I should have been more considerate. But I didn’t know how to be. I was short at her. Now I know it wasn’t her fault. Now I know different”.*

“Taking part in these things [Age Scotland general public training] also helps to prompt talk amongst tenants”

Lead Worker at Trust Housing Association

e) Older people have particular dementia aware needs

However, there is some way to go before dementia aware knowledge becomes common place. Evidence gathered suggests that the training for older people could be more powerful if it were a series of training throughout the year rather than a one-off instance of training. For example, older people in the research stated:

- *“I don’t think it can be prevented”.*
- *“I would like to know more about [dementia]. What happens?”*
- *“I can’t recall the quiz. Bingo neither”.*
- *“How much exercise do you need to do to help to prevent it?”*
- *“I’ve got dementia and some people have supported me. Others just laugh. I find a lot of people like that. It’s because they are afraid and don’t realise what to do”.*

“Not a lot of people understand the basics. What to look out for. How to treat people. There’s a lot more to do when your Partner get it. There is respite care and help at home is available for carers. When I first started caring some ten years back, I was sleeping on the hall floor so as [John] my husband wouldn’t out of the house in the middle of the night”

Older female carer

SECTION 2.0 - GENERAL PUBLIC SURVEY FINDINGS

a) Level of dementia awareness

At baseline

When asked to describe their level of dementia awareness before the training course, 66% of respondents stated in the general public survey that they were partially aware of how to interact with someone with dementia, with only 10% describing themselves as fully aware. 23% described themselves as unaware.

In the post evaluation (3-9 months interval)

Following the training course, 41% cited that they were fully aware of the signs and symptoms of dementia and how people can live well with dementia an increase of 31%. The number of participants who were partially aware dropped by 10% to 56%.

Only 1.5% of respondents stated that they were unaware of the signs and symptoms.

b) Signs, symptoms and risk factors

At baseline (immediately after training)

Findings show that 78% of participants (n=379) knew over five signs and symptoms of dementia following Age Scotland's intervention, with 17% citing that they knew over three signs.

Survey findings also indicate that attendees have an understanding of the risk factors of dementia.

This is supported by findings that show that participants could correctly identify risk factors for dementia, with 98% selecting smoking, 97% citing that high alcohol consumption, 96% physical inactivity and 94% citing mental inactivity. 'Drinking coffee' and 'being male' (inserted into the survey question as 'deliberate placebo' answers) were both identified as false risk factors by respondents. Less than 12% selecting coffee consumption and 7% of respondents choosing 'being male'.

When asked to rate how valuable the training was in terms of improving knowledge about signs and symptoms of dementia, less than 4% of respondents rated their knowledge below 4 on a scale of 1 to 7 (1 being little/no knowledge and 7 being extremely high knowledge about signs and symptoms of dementia). Remaining participants rated the training with a score of 5 or more.

In the post-evaluation (3-9 months interval)

Post-evaluation findings about signs, symptoms and risk factors change substantively with the majority of Participants (n=64) who answered this question reporting they now knew

over three signs and symptoms of dementia following Age Scotland's intervention (increase of 18%) and 34% citing that they knew over five signs (decrease of 44%).

The findings also indicate that training attendees recall of the types of risk factors of dementia also slightly change.

For example, 89% of respondents select smoking (decrease of 10%), 91% cite high alcohol consumption (decrease of 8%), 97% indicate physical inactivity (increase of 1%) and 100% cite mental inactivity (increase of 6%) as risk factors.

In addition, 64.5% of respondents indicate that they have implemented the tips shared during Age Scotland's training to reduce their personal risk of dementia.

The most common tips to be shared by participants included increasing physical activity (69%), doing regular mentally challenging activity (55%) and increasing social activity (45%) with 38% reporting that they had shared modifying diet with others.

c) Organisational and personal change

At baseline (immediately after training)

Age Scotland's dementia awareness interventions were rated by 69% of respondents as very likely to make organisations and networks more dementia aware.

Out of 492 participants, 95% said they would now give a person experiencing dementia symptoms enough time when they find a task difficult and 76% felt they would know which organisations could provide information and advice. 90% of people also said that they would now be taking steps to ensure their group (Age Scotland's Member Group) would become more dementia aware.

Where personal change was concerned, 96.5% of participants rated their knowledge about dementia between 5-7 on a scale of 1 to 7 (1 being little/no knowledge and 7 being extremely high knowledge about dementia).

89% of respondents (n=485) also stated that when they next encounter someone with dementia, they are likely to speak in simple sentences, 80.5% said that they would take things slowly while 51% would rephrase what they say if it is not first understood. Whilst 40% of respondents indicated they would speak to the person experiencing dementia directly and not to another person/carer accompanying them.

Further, out of 490 responses, 340 indicated that it is very likely that they could use some or all of the techniques learnt to support people to live well with dementia and rated the training with a score of 6 out of 7 on a scale of 1 to 7 (1 being unlikely and 7 being extremely likely to use). Less than 8% of respondents indicated a score between 1-4 on the same scale.

In addition, Age Scotland's dementia aware training intervention was also rated highly by participants who self-reported that their ability to communicate with someone with dementia had improved.

40% rated the training with a score of 6 on a scale of 1 to 7 (1 being unlikely and 7 being extremely likely to improve ability to communicate), while 29% gave a rating of 7. Less than 6% of respondents gave a score between 1-4.

In the post evaluation (3-9 months interval)

Findings for interacting with people experiencing dementia differ from the baseline in some personal and organisational areas.

This is mainly because 63% of respondents indicated that they had not yet encountered someone experiencing dementia symptoms, which affects findings because of a limited opportunity to support someone and report any action/s in the post-evaluation survey.

For example, of those responding, 78% said they would now give a person experiencing dementia symptoms enough time when they find a task difficult (a decrease of 22%) and 42% felt they would now know which organisations could provide information and advice. 80% of respondents also said that they would now be taking steps to ensure their Group would become more dementia aware (decrease of 10%).

Plus, of those who indicated they had used activities and tips recommended in the training, 89% stated that they had listened more carefully when they encountered someone with dementia and 86% stated that they had spoken more slowly and clearly, repeating back anything when asked to do so. 84.5% said that they had remained calm and friendly when speaking to someone with dementia and 74.5% indicated that they had spoken to the person experiencing dementia directly and not to another person/carer accompanying them.

Further, 36% of respondents stated that they had used the activities and tips said they had done so up to twice a week with 13% stating they used them every day. Less than 17% stated that they used the tips twice a year.

67% of participants rated their knowledge about dementia between 5-7 on a scale of 1 to 7 (1 being little/no knowledge and 7 being extremely high knowledge about the dementia topic) a decrease of 30% overtime.

When describing how much they know about the signs and symptoms of dementia, 52% cited that they know over three and 34% selected that they know over five.

For example, when asked to indicate risk factors of dementia, 100% of participants selected mental inactivity, 97% (a decrease of 3%) cited physical inactivity, 85% chronic depression, 89% smoking and 92% high alcohol consumption.

Interestingly, 65% of respondents suggested that they had implemented tips shared during Age Scotland's dementia awareness training to reduce their own personal risk of developing dementia.

Most reported that they had increased their physical activity (69%), 55% reporting they were doing regular mentally challenging activity like crosswords and 45% stated that they were getting out more to do social activity.

Lastly, on a scale of 1 (low capability) to 7 (very high capability), 49% rated their ability to help someone with dementia to live life well as 5 (increase of 29% on baseline findings), with 19% selecting 4 (increase of 15%).

d) Intervention expectations and value rated by respondents

At baseline

45% responded that the dementia aware training met their objectives fully, and 26% indicated that their expectations were exceeded.

Survey findings show that participants had varied expectations of the day, however, many mentioned that they expected to learn about the symptoms and causes of dementia, as well as to gain an understanding about how to deal with dementia and support the needs of those living with it. Illustrative quotes from participants collected are below.

- *“To learn more about dementia to put into practice within my work, mostly by being better able to identify issues and signpost to relevant support”.*
- *“To gain a basic working knowledge of the main types of dementia and their effect on different parts of the brain, and to discuss communication techniques and how to plan inclusive events and activities”.*
- *“To learn more about symptoms and signs of dementia; how to support people living with dementia; how to support their needs while attending/participating in creative activities”.*

In the post-evaluation (3-9 months interval)

It was not relevant nor timely nor appropriate to ask this question in the post-evaluation at a 3-9 month interval.

CHAPTER 4: EMPLOYER/WORKFORCE FINDINGS

Background

This chapter describes evidence from both the qualitative research (focus group and depth interviews) as well as their surveys and is divided into two sections.

Section 1.0 describes focus group and depth interview findings with attendees of employer/workplace training. **Section 2.0** details Employer/Workforce survey findings.

This evidence suggests that Age Scotland's dementia aware training had multiple effects. Participants in the training indicated they had been impacted in terms of knowledge and learning improvement about dementia, had been prompted to take or adjust action/s to reduce their own personal risk of getting dementia and it had motivated them to use the tips when speaking to those who may be exhibiting early signs of dementia to include them in social and workplace settings.

These are described in more detail next.

SECTION 1.0 - FOCUS GROUP AND DEPTH INTERVIEW FINDINGS WITH ATTENDEES OF EMPLOYER/WORKPLACE TRAINING

a) Overall learning of participants to the dementia awareness training

Evidence suggests that Age Scotland's dementia aware training intervention had multiple effects in knowledge and learning improvement about dementia. For example, participants stated:

- *"This was the most effective training course I have been on. The role play situations were particularly helpful and as a team leader, they made me think about how I would cope if one of my team was showing signs of dementia"*.
- *"The course has made us focus on how well equipped we are to be able to help support a colleague with dementia and what we need to put in place"*.
- *"Managed to successfully tread a very fine line between being scary and fascinating"*.
- *"Handled a very difficult subject with respect and sensitivity"*.
- *"The most thought provoking training we have done as a team"*.
- *"I was astonished by the range of types of dementia - I only knew about vascular dementia and Alzheimer's"*.
- *"I had no idea dementia affected balance and how you see your surroundings differently"*.
- *"Didn't know that younger people could suffer from dementia"*.

- *“I thought dementia just made you forget things. Didn’t know what it does to your body”.*
- *“It’s good to know there are things you can do to keep your brain performing well even if you have dementia”.*

“This was the best training course I have been on. I found it fascinating and I think about it regularly when I am dealing with our customers who have dementia”

Glasgow Film Theatre Training Participant

b) Overall behaviour of participants to the dementia awareness training

Evidence suggests that Age Scotland’s dementia aware training intervention prompted behaviours in the workplace for organisations and their employees to be more dementia aware. For example, participants indicated:

- *“It must be very difficult to cope with a relative who has dementia. I will try to help colleagues who are going through this by asking how they are doing and being a shoulder to cry on if that would help them”.*
- *“We need to look at the processes we use to performance manage someone with dementia”.*
- *“We could potentially have a lot of staff members who will need to go part-time in the next few years to look after relatives. That would have a big impact on us and we need to make sure we can support them properly and that our HR policies reflect this”.*
- *“We now have a carer’s network so that colleagues have someone they can go to talk to if they are having a bad day. We can all help with this”.*
- *“I now watch out for signs of dementia when I am meeting clients for the first time”.*
- *“There was a lady on my bus the other day who was clearly a bit lost and disorientated and I was able to help her because I remembered what the trainer had said about to speak and guide someone with dementia. I would have been scared that I was making things worse before!”*

“Those of us that went on the course have been able to have in-depth discussions about the difficult and sensitive issues that dementia raises - we would never have done that without going through the training”.

Scottish Prosecution College Training Participant

c) Motivation of participants to the dementia awareness training

Following participation, motivation levels to improve employee behaviour and/or that of their organisational culture to be more dementia aware and inclusive at work were far higher according to the research findings. For example, participants who attended Age Scotland’s Employer/Workplace dementia aware training indicated:

- *“The course has made us focus on how well equipped we are to be able to help support a colleague with dementia and what we need to put in place”.*
- *“As a team leader I was keen to learn how I could support one of my team if they were showing early signs of dementia”.*
- *“I have witnessed dementia at first hand and wanted to know more”.*
- *“It could happen to any of us so it’s good to know as much as possible”.*
- *“Everyone deserves the chance to stay in work and I wanted to find out what I could do to help”.*
- *“I have said to colleagues that they should do this training if it is offered”.*

“I wanted to understand the issues involved in handling difficult conversations about the capabilities of colleagues with dementia”

**Scottish Children’s Reporters Administration
Training Attendee**

d) Overall Results of participants to the dementia awareness training

Attendees of the Employer/Workplace training delivered by Age Scotland summarised the results of their attendance in a number of ways. These ranged from acknowledgement of organisational policy (for carers and HR support), directly for how dementia can affect the delivery of their work and about ensuring more colleagues had opportunity to attend future training of this nature. For example, attendees of the training reported:

- *“I am trying to support my colleagues who are carers in a more practical way”.*

- *“It is on my radar now when I am looking at family cases”.*
- *“The challenge is how to support someone to stay in the workplace without them losing status by moving to a lower grade job”.*
- *“I know a lot of people who are coping with a relative’s dementia and I think I can help them a bit more now”.*
- *“We are looking at how dementia could affect grandparents who are looking after children in place of their parents”.*
- *“The scenarios have prompted conversations that would have been difficult to initiate before the training”.*
- *“I have said to colleagues that they should do this training if it is offered”.*
- *“It would be good to go on a follow-up course”.*
- *“I loved the scenarios - they were close to what I am dealing with in my team”.*
- *“Are there any CPD plans for more in-depth learning about dementia in the workplace?”*

“It is vital that Age Scotland are able to continue delivering this training. The more people that understand how to cope with dementia in the workplace, the better”

Scottish Prosecution College Training Attendee

SECTION 2.0 - EMPLOYER/WORKFORCE SURVEY FINDINGS

Please note, due to the very small participant numbers in the post-evaluation survey for Employer/Workforce training (n=11), these findings are noted separately in Annex III for readers since they are not significant to the findings.

NOTE: due to the low number of respondents, post-evaluation Employer/Workplace findings must be read with high caution. Section 2.0 therefore only reports the baseline survey findings for the Employer/Workplace training.

a) Respondent profile

In the baseline

A total of 159 respondents completed the employer and HR baseline survey between June 2016 and April 2018 and there were 33 partial returns.

In the survey, 68% of respondents reported that they had attended the 'dementia in the workplace' training and 32% reported that they had undertaken the 'Dementia, the Law and Workplace Good practice' training. Both were delivered by Age Scotland.

40.5% described themselves as working everyday with customers, the general public and/or the elderly and 24.5% of participants reported that they were a manager, responsible for teams that work with customers/the public.

17% reported they were in a HR role, 4% a senior director and 9% reported that they were an employee and caring for someone who was experiencing dementia.

b) Dementia aware levels in Employer/Workplace survey

At baseline

27.5% of participants indicated that before they attended the training they would have rated their personal dementia awareness level as 'unaware' of how to interact with a person experiencing dementia, with 68% declaring that they were partially aware.

Only 4.8% of respondents noted that they were fully aware of how to interact with someone with dementia.

c) Understanding the signs, risk factors and symptoms of dementia

At baseline (straight after training)

To understand the effect of Age Scotland's training on attendees, the baseline survey explored what attendees knew about the signs and symptoms of dementia.

22% of respondent self-reported that they could now declare over three signs and symptoms with the majority of trainees rating their knowledge of dementia as re-calling over 5 signs and symptoms (77%).

Attendees at Age Scotland's dementia aware workplace training were also asked what those risk factors were. When responding, 92% of participants selected obesity, 97.5% indicated smoking, 95.5% chose mental inactivity and 95% cited physical inactivity as correct answers from a list of choices that some of which, were intentionally false.

‘Drinking coffee’ and ‘being male’ were the deliberate incorrect answers that were ‘planted’ as false answers in the risk factor selection list.

d) Organisational and personal change

At baseline (straight after training)

Personal change

When asked in the baseline survey, 40% of respondents attending Age Scotland’s Employer/Workplace training stated that they were more likely to improve their interactions with those experiencing early stage dementia following the training, scoring themselves 6 out of 7 on a scale of improvement. 26% scored themselves 5 out of 7 on the same scale.

Participants also rated the value of the training in terms of improving their knowledge about signs and symptoms of early stage dementia on a scale of 1 to 7 (7 being the highest knowledge score). Using this scale, 51% of Respondents rated the training 6 out of 7 and 31% 7 out of 7. Less than 2% rated the training with a score of 4 or less.

53% of respondents also stated that they could be more patient with older customers and 59% felt they could sign-post other employees to sources of dementia advice and advice for carers.

At the baseline stage, 44% of participants also reported that they were confident that they could implement dementia aware training for other colleagues, 25% reported that they could create a dementia awareness campaign for employees with leaflets and posters and 16% felt they could post dementia awareness onto the next Board agenda.

In addition, 42% stated that they could produce tip sheets for employees to advise them about how to support someone with dementia.

Organisational change

22% of those taking part in the baseline survey, rated their workplace as a 3 out of 7 for dementia awareness in its current situation.

28% of respondents within the baseline survey rated their organisation with a score of 4 out of 7 for dementia awareness with 22% rating their workplace as a 5 out of 7 (7 being the highest score).

Respondents were also invited to rate the effect of the training on their organisation both in terms of being more dementia aware or to improve their ability to communicate in a dementia aware way.

At baseline, 31% of respondents reported rated the training with a 5 out of 7 (7 being the highest) score for making an effect with 40% rating the course has being 6 out of 7. 12% of respondents rated the training effect as having a 7 out of 7 effect on their organisation. Less than 17% rated it below 4 on the same scale.

Participants were also asked to rate activities that they felt most confident to put into action. Both to improve how their organisation responds to people living with dementia and/or carers that support someone with dementia.

Of those responding, 36% reported they could better communicate existing HR policies that may benefit staff who are living with dementia or who are caring for someone with

dementia, 18% felt they could review HR policy to ensure they are dementia aware and 31% stated that they could improve how communication between staff takes place in their respective organisations.

Lastly, additional survey questions asked participants to rate the course on improving organisational approaches/policies to support those with dementia on a 1 - 7 scale of improvement where 1 was the lowest score.

26% rated the likelihood of the training to improve their organisation's approach as 5 out of 7 and 41% of participants rated the improvement of their organisation's approach as a 6 out of 7. A quarter of respondents (25%) rated the training with a score of 4 or less on the same scale.

e) Meeting expectations of respondents in Employer/Workplace survey

49% of training respondents mentioned that their expectations and training objectives had been met in full with 34% reporting that they had been exceeded. 8% mentioned that they had mostly been met.

Objectives given by respondents via the online survey regarding Age Scotland's dementia aware training ranged from those who hoped to find out more about causes, signs and symptoms, risk factors, and how to communicate and assist someone with dementia, reflecting the content of the course.

A selection of responses about their expectations collected between August 2016 and June 2017 are summarised next:

- "Find out more and to learn more about dementia (NOTE: *this was referenced as the top objective and/or expectation of the training*)".
- "To learn the early warning signs of dementia and how best to interact with those living with it".
- "To learn the rights of carers and individuals with dementia in the workplace"
- "How to adapt to help those living with dementia".
- "To learn about how dementia is diagnosed, the different types of it and the signs/symptoms that could affect a client's capacity".
- "To learn what Dementia is, the types, symptoms and causes and how I can help in my job".

The survey asked respondents to reflect on the value that Age Scotland's dementia aware intervention had on respondents in terms of improving their knowledge levels. 59% of respondents rated the sessions with 6 out of 7 (7 being the highest score). A positive 33% rated it as 7 out of 7.



CHAPTER 5: SUMMARY ANALYSIS OF FINDINGS

1.0 OVERALL REFLECTIONS BY PARTICIPANTS TO THE DEMENTIA AWARENESS TRAINING

The qualitative research evidence points to a number of learning, motivation and behavioural impacts resulting from Age Scotland's dementia aware training on participants interviewed. Overall, the research findings suggest that participants remembered a lot of detail from the training course content and have been urging colleagues to attend if it is offered again by Age Scotland.

For example, the Special Project Research with Trade Union representatives suggests that participants have taken their knowledge and learning from the training course offered by Age Scotland. In some instances, the improvement in knowledge and learning has led to an increased motivation to take action leading to the organisation of information and awareness days, conversations with HR teams as well as motions about dementia inclusion in the workplace being developed and passed at the STUC conference.

In addition, nearly all participants place a high value on the content of the training according to the research evidence. Many express the view that Age Scotland's dementia aware training should be rolled out to as many public sector and large commercial organisations as possible where they believe it would have the greatest impact.

In summary, participants who attended both types of Age Scotland's Dementia Aware training believe it to have made a difference to them and how they understand the situation of carers who are caring for someone with dementia. Many participants also believe they are better equipped to deal in the instance where they may encounter someone with dementia.

The research also found that the training prompted discussions between colleagues, within teams and created greater understanding of the pressures and stress that those caring for a relative with dementia may be facing.

Almost all participants in the research found the dementia aware training thought-provoking and those involved in HR and training stated that it raised issues and scenarios they had never previously considered.

For example, one manager expressed how, after the training, he realised that the demographic of the staff in his organisation will probably result in many of them having to take on caring duties. He felt that the training had highlighted a potential problem area that he can now plan for to mitigate the impact on both employees and the organisation.

One of the Evaluation Interviewers reported that 6 people had been extremely anxious about attending the dementia aware training session.

One manager expressed how, after the Age Scotland's Dementia Aware training, he realised that the demographic of the staff in his organisation will probably result in many of them having to take on caring duties. He felt that the training had highlighted a potential problem area that he can now plan for to mitigate the impact on both employees and the organisation

For example, one female participant stated, *"Mental illness scares me, I am terrified I am going to get dementia and I didn't want to attend today. But I now feel I understand it better now that I've done this training. It would be nice to think that more people could do it so we could all help each other."*

Three people who had lost relatives to dementia stated that they had found attending the training emotional and it brought feelings of guilt and regret back for them *with one participant stating, "If I had known some of this when I was dealing with my Mum it might have made life better and easier for her."*

However, this did not prevent these participants learning from the training and one man commented that *"[Age Scotland] handled it all very sensitively and didn't let it become sentimental. Keeping it factual was good"*.

Findings show that organisations are determined to put more people through the training and two are looking at making it mandatory. All reported one or more impacts from the training and the issues it raised are beginning to be raised at senior level.

For example, one HR manager stated *"This is a wake-up call for us. We need to make sure we have everything in place to enable us to keep a colleague with dementia in work for as long as is practicable. Our struggle will be finding alternative job roles due to the high degree of accuracy needed as a result of the nature of our core function."*

For example, volunteers who took part in the focus group at the Glasgow Film Theatre expressed how the dementia aware training had encouraged the organisation to prepare and future proof both the organisation and its customer, *"I don't think the Movie Memories cinema screenings would have been so successful and popular as quickly if we hadn't been so well prepared before they started. The training gave us a good start and we have now built on that initial knowledge. It certainly made me more confident and relaxed about chatting to our customers and their carers. It has helped us give them a good time in the cinema"*.

“Dementia is a wake-up call for us. We need to make sure we have everything in place to enable us to keep a colleague with dementia in work for as long as is practicable. Our struggle will be finding alternative job roles due to the high degree of accuracy needed as a result of the nature of our core function”

Scottish Prosecution College

Evidence suggests that where the organisation and leadership is prepared to take action that there are more follow-up actions and organisational changes being planned for longer term implementation as a direct result of the information contained in the content of the training.

2.0 OVERALL LEARNING OF PARTICIPANTS TO THE DEMENTIA AWARENESS TRAINING

The most common response to the question ‘*What was the key learning from the training?*’ by participants was that the majority were surprised at the large range of types of dementia and what the range of symptoms can be. There was a definite perception prior to the training that dementia only affected someone’s memory.

There were a number of other learning points that participants in the evaluation research reported also. These are summarised below:

Key learning point 1) That the impact on the sensory capabilities of someone with dementia with many participants reporting how surprised they were that so many different types of dementia exist affecting a wider range of physical health matters.

Key learning point 2) That by making small physical changes to their workplace, teams could help colleagues with dementia to cope better on a day to day basis. For example, one participant said “*We are going to look at our corridors and public areas to see what we can do to improve them*”.

Key learning point 3) The knowledge that no two people’s experience of dementia will follow the same path and that some people will be impacted quicker than others and in differing ways.

For example, one team leader commented “*That makes it a bit harder to deal with because you can’t have a one size fits all plan [to support workforce plans]. With something like cancer you know that the person may have surgery then chemo. This is different, its unpredictable and that could be a challenge for us*”.

Key learning point 4) How the legal aspects of dementia under the Equality Act highlight potential problem areas around how to performance manage colleagues with dementia. For example, in the qualitative research, participants discussed whether it was

appropriate to use performance management processes. Some noted that they may look at using capability assessments in these cases.

One manager confided in one of the Group's that:

"We are currently facing this exact situation with an employee.

"The biggest problem is that the person cannot remember the previous meetings we have had and disputes the records/minutes and what was discussed. We have not been trained in handling these challenging one to one conversations in terms of performance management.

"It also raises difficulties around confidentiality when there are grumblings from others in the team that person X isn't pulling their weight but is seen to be being treated differently from anyone else in the team. It's difficult because the condition of dementia is not physically apparent".

"We now have a dementia ambassador [someone with dementia who comes to advise on what it's like from her side] and she is very good at pointing out little things we can do to make people who may be experiencing early signs of dementia to feel more relaxed. I find myself dealing with people more sympathetically, even at bus stops and in the shops now"

Glasgow Film Theatre

3.0 OVERALL BEHAVIOUR OF PARTICIPANTS TO THE DEMENTIA AWARENESS TRAINING

Participants reported that they were able to put what they learned on Age Scotland's Dementia Aware training into practice very quickly and practically. Most are using the techniques picked up from the course regularly which underlines the findings from the survey.

As well as creating a calm and relaxed physical environment, the Glasgow Film Theatre volunteers are now very aware of their body language and how they approach their customers with dementia since attending the training.

For example, one volunteer said *"I remember not to encroach too much on the person's physical space if I am trying to help someone. It can make them anxious and distressed if they feel you are crowding them."*

The research also points to organisational differences have also been instigated by organisations that have cascaded the dementia aware training throughout their teams/divisions to be more dementia aware.

One of the organisations reported that *“We now have a dementia ambassador [someone with dementia who comes to advise on what it’s like from her side] and she is very good at pointing out little things we can do to make people who may be experiencing early signs of dementia to feel more relaxed. I find myself dealing with people more sympathetically, even at bus stops and in the shops now.”*

Team leaders from all organisations canvassed in the research also reported that they have tried to be more aware of the pressures that some of their team members may be experiencing as a result of coping with a relative who is experiencing dementia.

For example “I can now spot when X who is a carer has been up during the night and had to go up to help her dad cope with her mum who has dementia. After the training I had a chat with her over a coffee and asked her what she found hardest to deal with and she said it was trying to be emotionless about it at work.”

a) Carer behaviours as a result of the dementia aware training

Although there is a willingness from organisations to keep carers or people with dementia in work for as long as possible, team leaders and managers realise that both situations put an additional strain on other team members and that it can lead to resentment when workloads increase as a result.

This is typified in much of the data collated, an example of which is, *“[A carer] now knows she can come and have a wee cry and a hug and that I understand why she needs to do it. I feel bad that I didn’t pick up on all this before. Any of us could be in that position.”*

The research evidence also suggests that it is also challenging for colleagues to have to keep checking, surreptitiously, that the person who is experiencing dementia or who is caring for a relative is not making mistakes at work.

One participant said, *“We are currently trying to support a colleague with dementia and it is not easy. Following the training, I have noticed other members of staff trying to put some of the things we learned into use when they are talking to her. I now make sure that when I am talking with her, I do it in a quiet area and I check her understanding regularly to keep the task fresh in her mind.”*

The overall feedback in the research from carers has been positive. As one carer put it, *“We have a very good carers policy and when I have had to take time off to cope with difficult situations relating to the care of a close relative, I feel I can now open up to my colleagues when I feel low about it. Because it came out very easily during talks we had following the training as people understood more.”*

4.0 OVERALL RESULTS OF PARTICIPANTS TO THE DEMENTIA AWARENESS TRAINING

When the learning from Age Scotland’s dementia aware training is followed up by organisational and personal opportunities to put the dementia aware training into practice adjustments of behaviour/s towards someone with dementia occur in a more positive and understanding way.

All organisations report in the evaluation that they have taken a number of actions as a result of the training.

For example, the Scottish Prosecution College (SPC) has created a support network for employees who are caring for relatives or partners. This is not exclusively for those caring for people with dementia but it is a key focus.

SPC hopes that by understanding the impact the caring duties can be having on a staff member, they can create a relevant and supportive policy which meets the needs of both the business and the individuals. They are also looking at changing the décor in the corridors and office areas to make them more suitable for people with dementia.

Age Scotland's training has also enabled middle managers to take the resulting knowledge and issues to senior management and prompted them to highlight the potential risks to the organisation and the duty of care for staff.

One of the key results of this is high level discussion is that what type of a fair route to take when handling performance limitations resulting from the impact of dementia on an employee is being considered by the organisation.

This is an area that most organisations signaled they would like more support with and suggested that a network could be set-up comprising businesses and organisations who had participated in Age Scotland's training, pointing to particular benefit for HR Managers.

Another example of this is the Glasgow Film Theatre. The Glasgow Film Theatre had been awarded funding from Life Changes Trust to launch a monthly dementia friendly cinema programme, *Movie Memories*. The Project has been put into place because many people with a diagnosis of dementia fear that they will no longer be socially welcome and stop taking part in activities they enjoy.

The *Movie Memories* programme looks to address this with inclusive and friendly screenings, dementia friendly venue and dementia aware staff and volunteers. This programme would not work without the staff and volunteers knowing how to interact effectively with customers and Glasgow Film Theatre's has a Programme Engagement Coordinator who has recruited volunteers and put the entire team through Age Scotland's training. The Coordinator points in the research that the *"Board believe there is a social duty to make sure people with dementia still have the choice to engage with activities that give them pleasure and we live and breathe that"*.

Glasgow Film Theatre is the first cinema in Glasgow to run this type of dementia aware programme and by working with a *Movie Memories* Coordinator, they have been able to refine the content of the cinema sessions and the way they are run from a logistical aspect.

As one participant in the research held at Glasgow Film Theatre, *"We have worked with the projectionists and have found the high and low spots of acoustics making the cinema experience better for people with hearing difficulties"*.

Similarly, by making the lights slightly brighter, people have no fear in getting around the cinema if they have dementia. *"Together, we found the barriers and then created solutions with people with dementia to make the Glasgow Film Theatre an enabling environment. Movie Memories means that people like me are included."*

5.0 OPPORTUNITIES AFFORDED TO PARTICIPANTS IN THE DEMENTIA AWARENESS TRAINING

All organisations would like to cascade Age Scotland’s dementia aware training out to all staff in due course enhancing the opportunities for learning about dementia exponentially in these organisations.

For example, the Scottish Prosecution Service are making the training mandatory for all employees.

Whilst many employees will have encountered family members with dementia, it was apparent that younger employees might not have the same understanding or empathy of the problems a colleague with dementia could be facing and this could be a key target group for employers to tailor future dementia aware training.

a) Involving Human Resources

Since many of the practicalities of keeping someone with dementia in the workplace are the responsibility of Human Resources departments, one observation from a participant was *“It would be beneficial to ensure that someone from HR is present in training sessions to answer questions (especially in scenarios) and to give statutory guidance.”*

b) CPD recognition

Often managers and HR/Team Leaders expressed the wish for CPD around dementia and wondered if Age Scotland had an opportunity to *“Develop a mechanism for flagging up changes in law, best practice, treatments and understanding of the condition and for sharing information across sectors [such as CPD].”*

c) Case studies as instruments for learning

All participants interviewed made reference to the scenarios used in the training.

They encouraged good discussion and related to real-life situations currently being experienced in two organisations. There is a genuine desire amongst the participants to gain further knowledge about dementia in the workplace and they view Age Scotland as a trusted source for information. Multiple participants referred to the case study involving the ‘young man’.

This case challenged their perceptions and stereotypes and research evidence suggests that the training could be enhanced if how other organisations had dealt with specific cases like these could be very helpful to learn both ‘pros’ and ‘cons’ of the work.

d) Involvement of corporate employee representatives and unions

The continuing support of the Unions for the training was viewed as being very important and all three organisations hoped the uptake from commercial, charitable and social enterprise organisations would increase.

6.0 ENHANCED MOTIVATION OF PARTICIPANTS IN THE DEMENTIA AWARENESS TRAINING

Several participants had personal experience of losing someone close to them to dementia and wanted to find out more so that they could help others.

Some people who were offered the training did decline it for personal reasons *“a bit too close to home just now”*. For one lady her motivation was *“So many of my pals are going through this with their parents just now that I thought if I do the training I’ll be able to understand what they’re going through a bit better. I don’t want to say the wrong thing to them out of ignorance.”*

Team leaders wanted to go on the course to gain knowledge and insight into how to handle the difficult conversations that they might have to initiate with a member of their team. They also wanted to be able to spot some of the early signs of dementia. One team leader did comment *“I think we have to watch that we don’t become obsessed with attributing everything to dementia. Someone might just be going through a bad patch for a whole number of reasons and be a bit distracted.”*

This is a highly emotive subject and most participants did admit to being very apprehensive at the start of the training. Not surprisingly, when interviewing the male participants it was clear that they were more uncomfortable than their female colleagues about taking part in the training. *“I’m not very good at showing what I am feeling and don’t like situations where people get upset so I was worried that it might all be a bit touchy feely. It wasn’t! I am glad I went because I wanted to find out more about dementia. So many people seem to have it now.”*

For the Scottish Prosecution College a key motivation for going on the training was to ensure that they were following best practice when dealing with someone with dementia’s capabilities in the workplace. They also want to be able to equip their trainees and students with the most up-to-date legislative employment rulings. *“We need to set an example to the legal sector and by learning more about the subject we can help to encourage others to participate”*.

Both SCRA and the Scottish Prosecution College want to ensure that their employees are able to deal effectively and sympathetically with members of the public who are their clients and who may be exhibiting signs of dementia. *“We have a duty to the public to ensure that everyone is treated fairly and appropriately”*

The volunteers from Glasgow Film Theatre all wanted to do the training to ensure that the Movie Memories project was a great success and that they could help the customers and their families/carers have the best possible experience.

7.0 AGE SCOTLAND'S DEMENTIA AWARE TRAINING AND TRADE UNION REPRESENTATIVES

It is unsurprising that Union representatives who were interviewed in the depth interviews have a slightly different view point regarding the value of Age Scotland's dementia aware training when compared to the viewpoints of employees themselves.

Views in the research largely centred on the rights of workers being already enshrined but there are barriers to 'activation of those rights' in a public and more senior corporate context

This is because of the nature of their role as representatives of a national movement that is upholding and supporting worker's rights with management and senior decision-maker inputs.

Overall, there were two distinct findings from Trade Unions when compared to the qualitative research findings with employees.

Firstly, one distinction was how equality legislation could be used to prioritise the rights of those with a diagnosis of dementia and their carers in the workplace.

A second distinction was how participant views centred on lowering the barriers to 'activate' those rights as part of a cultural movement, enlisting the help of a senior corporate context.

For example, findings suggest that Trade Unions may have a weaker relationship when upholding equalities law where dementia is concerned because it is not a popular issue or one that is high profile. This finding was based on the belief held by some participants that the tradition of voluntarism or 'opting-in' to adopt more dementia aware practices may mean patchy adherence and slower development of organisational dementia aware policy.

Some representatives also report that there are historic and contemporary tensions between the collective bargaining functions of Trade Unions and their engagement with individualistic, rights-based equality legislation on single issues like dementia.

Findings with Trade Union representatives also suggest that there are both financial, time and prioritisation issues that are particular to Trade Unions which affect decisions that are made before embarking on a rights-based approach to inclusive work spaces for employees who may be experiencing dementia symptoms.

Very interestingly, many Union representatives interviewed report that during the course of their work where dementia is a factor that a clear gender imbalance exists.

“We now have low level dementia awareness in our organisation but there is little going on to proactively support it because other issues just take precedent”

Communications Worker Union Representative

According to participants in the research, this imbalance adversely affects women more than men.

Participants reported in the research that women are often the main care giver to a person or relative with dementia, the typical person in households in Scotland who has usually made the least pension contributions during the course of their career so are least able to manage financially when they or a relative experiences dementia and who are more likely to be working part-time on lower pay because of previous or current care-giver roles.

More generally, the findings with representatives suggest that a wider roll-out of the dementia aware training to larger organisations at no cost by Age Scotland could more than likely gain higher recognition from senior decision makers of the value of dementia workplace policies and as a campaign issue.

Putting this point into words one Representative from Unison mentioned, *“In Scotland, Trade Union politics clearly plays a role in decisions about if or how gender pay and pension equality will be pursued, but there are other influences like more trendy corporate and legal matters surrounding period poverty, disability or mental ill-health that grabs the prioritization list making it harder to get Management and HR [of organisations] behind the [dementia] issue. Training for far higher numbers of people [workers] in larger organisations would help to penetrate that”.*



CHAPTER 6: CONCLUSIONS AND IMPACTS

This Chapter has two sections. Section 1.0 details overall conclusions made in the research, including dementia awareness in organisational settings, dementia awareness and internal and external organisational barriers, dementia awareness and Trade Unions and dementia awareness and gender balance and levels of dementia aware action within organisations is regularly reliant on local leadership.

Section 2.0 covers evidenced impacts.

SECTION 1.0: OVERALL CONCLUSIONS

a) Overall conclusions

The majority of respondents taking part in the ‘general public survey’ are those already involved in older people issues and care which does mean that knowledge levels are likely to be moderately higher than if conducted with a member of the general public for example.

Given this, respondents rated their dementia awareness to be high (76%). However, respondents who reportedly had high dementia awareness levels also reported the greatest intention to take action or had taken action to reduce personal risk by reducing alcohol, taking more physical and/or mental exercise.

This outcome is strongly supported by the evidence that shows participants reported that they have been implementing tips shared during the training delivered by Age Scotland for reducing their own risk of developing dementia, with up to 69% citing that they have taken action to reduce personal risk.

Of those respondents who have encountered and/or helped someone who they believed to have early stage dementia and/or who is experiencing dementia, most reported that they have aimed to communicate with that person differently. Choosing to speak to them directly, remaining calm, and giving them enough time to respond. However, most respondents also believe they have not yet encountered anyone with dementia to trial and/or use the techniques they learnt.

Survey results also show that good strides have been made in raising dementia awareness levels within the employer/workplaces where interventions have been delivered. In the post evaluation survey, participants were asked what top three actions they believed were being implemented and/or they could put into action within their workplace. These actions were to improve how their organisations responded to people living with dementia or caring for someone with dementia.

Of those responding, 82% responded that had shared what they had learned with colleagues, 74% reported that they would communicate better with customers and clients and 51% reported that there would be more dementia awareness training for staff.

In the post evaluation survey, findings also show that of the top three actions they believed were being implemented and/or they could put into action within their workplace, 82% responded that had shared what they had learned with colleagues, 74% reported that they would communicate better with customers and clients and 51% reported that there would be more dementia awareness training for staff.

The Employer survey also asked respondents to rate the extent that the training had on attendees' confidence to progress a new policy, approach or training course to help those with dementia.

Of those responding to this question, 31% rated the course as having a 5 out of 7 (7 being the highest) score on their confidence. 38% reported it having a 6 out of 7 effect and 31% reported it as having a 7 out of 7 effect on their confidence level.

b) Dementia awareness in organisational settings

Special Project Research in the evaluation found that organisations were prompted to attend Age Scotland's dementia awareness training because they were actively managing large-scale dementia needs as part of their everyday business. Such business needs concerned either their members or tenants. Whilst senior management and HR participants were aware that the organisations they worked for needed to do more to comply with equality legislation and looked at dementia awareness training and practice as a risk reduction and continuous professional development matter.

Many participants reported that they were either caring for or had someone in the family with dementia. This situation had acted as an added incentive to learn more about dementia awareness and prompted more follow-up action in their respective organisations.

Much of the follow-up action/s flowing from Age Scotland's training itself had entirely been generated by the attendee's personal motivation level to deliver medium to longer-term dementia aware activity

As one participant stated, *"If I had known some of this [about dementia awareness] when I was dealing with my Mum it might have made life easier at work for her and sustained her in work for longer. Better and easier for me and her when I look back on it."*

Most participants in the research noted that the training had been of value in differing ways professionally and personally. Though most pointed out that they had not been prompted until the Evaluation Research Interviewer called to set up follow-up research to review their initial dementia aware action plans, renew dementia aware activities and/or take their original plans forwards within their respective organisations. This means that much of the follow-up action/s flowing from Age Scotland's training itself had entirely been generated by the attendee's personal motivation level to deliver medium to longer-term dementia aware activity.

Evidence in the evaluation also suggests that senior management and leadership teams become prepared to take action when there are more follow-up compliance prompts and/or organisational changes being planned.

Findings also suggest that there are financial, time and prioritisation issues internally and externally to organisations that prevent them embarking on rights-based approaches to inclusive work spaces for employees with early-stage and dementia diagnoses.

c) Dementia awareness and internal and external organisational barriers

Findings suggest that there are a number of internal and external barriers to increasing the degree and number of dementia aware workplaces in Scotland.

External barriers perceived by research participants include the low priority perceived around dementia in the workplace, especially against more popular campaign topics like LGBTIQ, race and mental health issues for example. Plus there are also stigmatising perceptions about capabilities of employees with a diagnosis of dementia, as well as whether dementia is covered specifically by equality laws.

Internal barriers perceived by research participants include how workplaces can be made more alert to dementia issues overall and how HR and advocacy/carer workplace networks are prompted to take dementia and carer matters more seriously, seeking to develop workplace policy and the activation of rights-based approaches for those experiencing dementia and that of their carers.

One solution noted by some research participants to overcome both internal and external barriers is the development of 'reflexive regulation' in the form of Public Sector Equality Duties. This is seen by Union representatives in particular as beneficial because such duties do not depend on large-scale, adversarial legal interventions in court. Making these approaches more time and monetarily efficient.

The most important point to note about the Public Sector Equality Duties according to some participants is that they were unlike any previous equality legislation in that they did not provide additional rights for individuals but rather placed responsibilities on public authorities and larger workforces to provide supportive mechanisms to create future workforce management.

In this respect they were considered to be a positive, proactive approach to equality which did not depend on discrimination having already taken place. They did not replace the existing equality legislation, which still provides legal remedies for individuals who have suffered discrimination. Rather they sought to pre-empt legal cases by requiring public sector employers to anticipate and address potential sources of discrimination before cases emerged. For the improvement of workplaces to be dementia aware, this type of approach was noted by participants as a possible important step.

Equally, these type of approaches have a proven track record and have been beneficial to lowering both internal and external barriers pertaining to racial equality, setting a helpful precedent that can be referred to and possibly utilised to improve dementia awareness in Scotland.

d) Dementia awareness and trade unions

Survey interviews and depth interview research with Trade Union representatives found that Age Scotland's training prompted a number of important discussions between Trade Union colleagues, employees and HR personnel in a number of large workplaces in Scotland.

“Unions can act as positive mediators of legislative equality frameworks and could be ‘written-in’ to more proactive legal measures”

Unison Union Representative

These conversations are reported as occurring within teams and middle and upper management tiers, often creating greater understanding of the pressures and stress that those caring for a relative with dementia may be facing and/or an understanding that dementia awareness would be a future workforce matter that organisations may need a policy and guidelines for.

Research with Trade Union representatives also found that the dementia aware training delivered by Age Scotland had struck a professional and personal chord with many representatives finding it to be thought-provoking and an issue that they had raised with HR on return to their respective workplaces.

Participants often referred to the strong role of HR being needed to:

- Action and ‘activate’ dementia friendly workplace policies where they existed
- Instigate the development of workplace dementia aware policy/s where they did not exist and
 - Cascading both policy and action across the organisation

Special Project Research with Trade Union representatives also found that the relationship between Trade Unions and equality legislation in Scotland needs to be could be utilised in such a way to re-prioritise the rights of those with a diagnosis of dementia in the workplace. This is because whilst rights for those with dementia and their carers are already enshrined, proactive support and ‘activation’ of those rights’ remains ad hoc or dormant.

e) Dementia awareness and gender balance

Many Trade Union representatives interviewed report that during the course of their work, where dementia is a factor, that there a clear gender imbalance exists. According to participants in the research, this imbalance adversely affects women more than men.

Participants report that women are often the main care giver to a person or relative with dementia, the typical person in households in Scotland who has usually made the least pension contributions during the course of their career so are least able to manage financially when they or a relative experiences dementia and who are more likely to be working part-time on lower pay because of previous or current care-giver roles.

The findings also suggest that Trade Unions have a problematic relationship with equalities law where dementia is concerned leading to what is commonly held to be a tradition of voluntarism or ‘opting-in’ to adopt more dementia aware work practices which leaves gaps in applying and upholding equality laws and policies for those with dementia and or their carers. Many participants pointed to the fact that voluntarism has a particular effect on women.

“Women get a triple-whammy where the topic of dementia is concerned. They are far more likely to fall foul of an absence or, or low adherence to, dementia policy in the workplace. This is usually because they are traditional care-givers, female and live longer... if they’ve had a family they have less pension contributions as they have either worked Part-time or given up work for a period of time to have children. They are also far more likely to have earned less over the long-term in addition. Then, as they grow older, they are far more likely to get dementia as they can live longer than men but be the least quipped to deal with it financially, socially or otherwise. We must do more about it”.

Prospect Union Representative

Alongside the gender imbalance sits the official and legal instruments for rights-based approaches and how equalisation of rights for women experiencing dementia and or being carers can take place.

Insights gathered within the depth interviews with representatives suggest that collective bargaining agendas on public sector pay occurs at the expense of equality priorities like dementia, adversely affecting wider equality matters like gender imbalance where

dementia is a factor. Whilst Union engagement with equality legislation has been positive in Scotland to date, especially with The Scottish Government on collective bargaining for pay, there are historic and contemporary tensions between the collective bargaining functions of Trade Unions and their engagement with individualistic, rights-based equality legislation on topics like dementia.

Interestingly, research findings also suggest that significant opportunities exist to engage senior management and leadership to further the development of dementia if dementia was ‘fused’ with the topic of gender pay, pension and carer policies.

f) Levels of dementia aware action within organisations is regularly reliant on local leadership

Retaining levels of awareness and action-levels following interventions delivered by Age Scotland are currently dependent on the levels of local leadership and personal motivations given in partner organisations, leading to ad hoc levels of follow-up action.

As one participant succinctly stated, *“We now have low level dementia awareness in our organisation but there is little going on to proactively support it because other issues just take precedent”*.

SECTION 2.0: EVIDENCED IMPACTS

The evidence suggests that there are several impacts arising from the evaluation findings.

Key impacts of Age Scotland’s dementia awareness raising work can be themed and these are listed below:

1. Capabilities of members of the general public, Age Scotland employees and other employees, as well as carers are viewed differently following participation and prompt action to become more dementia aware.
2. Actions by attendees of the training are undertaken to reduce personal risk of dementia via increasing physical activity, increasing mentally challenging and social activity.
3. Improved interactions with those experiencing early stage dementia take place.
4. Partnership working enhances organisational capabilities and workplaces positively change in places to be more dementia aware.

These emerging impacts are explored in more detail next.

Impact 1.0 Capabilities of Members, Age Scotland employees and other employees, as well as carers are viewed differently following participation

Evidence collated to date suggests that because of the high satisfaction ratings for Age Scotland’s activities, that matters learned by participants are passed onto others to share in that learning.

Findings suggest that members of the general public, Age Scotland employees and other employees, as well as carers are all more likely to view their capabilities differently once they have participated in Age Scotland's dementia awareness raising activities, *"Me? I'm doing more with others. Getting a bit more social. It makes you feel like it's OK just to sit and chat - the fact that it can be good for you [lowering risk of dementia] is just amazing. Really reassuring. It's not so much wasted time!"* and *"I now know that walking is not just making me fitter but also making my mind better"*.

This is linked to a very high % of satisfaction rate where participants state that they would recommend attending Age Scotland's Dementia Aware training to others like them to help them in to improve their understanding about dementia.

Findings to date also suggest that improvements in capacities of attendees develops as a result from attending Age Scotland's training. For example, improvement is reported to take place in both how to treat others experiencing early stage dementia and, about how to reduce personal risks of getting dementia. These findings also suggest that Members, employees and carers are more likely to view their capabilities differently once they have participated.

Differences that were reported by participants were improvements in the way in which Members, carers and Age Scotland employees understand, believe/think, approach and/or act towards someone with early stage dementia, improving aspects of a person's overall resilience when change/s are encountered.

As one participant reported, *"I look back and think I should have been more understanding with my wife Margaret. I should have been more considerate. But I didn't know how to be. I was short at her. Now I know it wasn't her fault. Now I know different"*

These findings are evidenced by both quantitative and qualitative research collected, collated and analysed to date.

Impact 2.0 Effectiveness in reducing personal risk via increasing physical activity

Data gathered suggests that the dementia awareness raising courses are offering detectable outcomes for Members, employees and carers in terms of reducing personal risk.

In particular, 'increasing levels of physical activity' resonates and recalls well in discussions with participants and was highly rated in the survey results. Socialising using games, tools and other settings, like excursion and visits, is the next most recalled action that participants wish to undertake to reduce their level of risk.

Dietary changes, including alcohol and smoking reduction is less memorable and not recalled unprompted, *"[Age Scotland's session] makes you more aware of what you're doing to yourself. Most of us have started walking more. I started walking out at lunchtime with these two [pointing at fellow participants]"*.

"I'm now doing a local sponsored walk. For four hours! It's to raise funds for our trip out. We're doing two this year instead of one".

Impact 3.0 Improved interactions with those experiencing early stage dementia

For example, findings indicate that participants associated with Age Scotland's dementia awareness raising activities improve in the following ways:

- Having more empathy with those who may exhibit and/or be experiencing early stage dementia.
- Carers report that they feel more able to comprehend the symptoms.
- Being capable to think about others who may be experiencing early stage dementia in a more positive fashion or treating them in a different way.
- Having a better understanding where dementia may stem from and its early signs.
- Feeling they have something to offer anyone experiencing dementia.
- Being more confident in living more independently/needing less key worker support.
- Getting involved in wider community activities like plays and choir.
- Feeling less scared/apprehensive of change in loved ones experiencing dementia.
- Giving permission to groups in social settings to discuss dementia more openly.
- *"I've been more compassionate to one of the residents in here. I now accept that he's not himself and it's down to the dementia".*

Impact 4.0 Partnership working enhances organisational capabilities

Whilst it is recognised that the social housing sector is proactive in regard to providing accommodation for those with early stage dementia and/or those caring for them, indicative findings from the depth interviews with Project Leads in Trust Housing Association, show that there are a number of professional development and organisational benefits as a result of Age Scotland delivering dementia awareness raising.

Where professional development is concerned, Age Scotland's activities in the Housing Association has stimulated further building-on existing programmes, helping to embed new activity or deepen existing activity.

Equally, Age Scotland delivering these sessions helps to stimulate professional development training from before and prompt new and/or embed learning from AS' training and from previous courses, *"Yes, we now do the Wii Fit. It was added after the training with Age Concern".*



CHAPTER 7: RECOMMENDATIONS

Given the research findings in this report, a number of recommendations are made. These are grouped into general public and Employer/Workforce recommendations. Please see these outlined below:

a) Recommendations for general public dementia aware training

- Consideration should be given to developing tailored guidance/poster/booklet support to older carers and older people within Age Scotland's Member Groups. Evaluation evidence suggests that those caring for someone with dementia often become informal experts to others about how to provide care and are at the sharp end of providing standards and quality of care for those with dementia.
- Evidence gathered suggests that the training for older people could be more powerful if it were a series of training throughout the year rather than a one-off instance of training. Expansion of the prevention of dementia and lowering personal risk element of the training to more regions in Scotland.
- Embark on public information campaigns about how to lower personal risk of getting dementia in Scotland, targeting higher risk groups i.e. smokers, binge drinkers, inactive and obese populations.
- Consideration should be given to enhancing partnership working with Age Scotland's Member Groups by co-designing guidance/poster/booklet support with older people and Member Groups about dementia awareness.
- Embark on tailored communications campaigns about how to support people with dementia, tailoring approaches to specific target audiences in Scotland. For example, communications could support carers when caring for a partner/relative at home with dementia how to live life well, smokers and young drinkers about risk prevention and commuters about what to do when you encounter someone with early stage dementia symptoms when travelling.

- Expand access points for Age Scotland’s general public training e.g. into community centres, public meetings/community and parish council meetings, leisure centres etc. for members of the public to attend.
- Compose practical guidance for Age Scotland’s Member Groups about how to approach and support Members exhibiting dementia symptoms and/or diagnoses at differing stages of progression of the condition.
- Member Groups should be encouraged and supported to set-up dementia aware networks and seminars in their local area to cascade knowledge, information, points of contact and support in their areas.
- Ensure that the symptoms of dementia and Alzheimer’s are distinguished further in any future training courses aimed at supporting the general public.
- Undertake further research into adverse effects on family relationships when working full-time and part-time whilst also caring for someone with dementia.

b) Recommendations for Employer/Workforce dementia training

- Tailoring of the dementia aware training intervention is needed to further support employers to make workplaces more dementia aware and to prompt sustained action within organisations over the medium to longer-term.
- Compose practical guidance for employers/managers about how to approach and deal with employee dementia diagnoses in light of equality legislation and workplace instances of dementia and caring for someone with dementia.
- Conduct research into how unions could work with HR and Senior Management within large workforces to uphold rights-based approaches and dementia aware policies in Scotland’s workplaces using collective bargaining approaches rather than voluntarism to make adherence to dementia equality policies more consistent. Examination of how this could be undertaken within equality law compliance within larger public sector workforces under Public Sector Equality Duties should be included.
- Consideration should be made to develop statutory CPD qualification/s for dementia aware training to maintain employee capabilities and level of dementia awareness overtime as well as retain knowledge levels and provide quality assurance. Particular emphasis should be placed on agencies in Scotland that are supplying contract care staff to those supporting people with a diagnosis of dementia and older people.
- Undertake further research into adverse effects of dementia on women in society should be explored to address inequalities reported by Trade Union representatives.
- Development of tailored dementia aware training to carers and care staff / Care supply agencies should be given some consideration. This should concern training / seminars about how to reduce personal risk and/or how to provide care for those with dementia. Both populations are viewed as being pivotal to the quality of life that someone with a diagnosis of dementia has.
- Consideration of how to improve response rate for any future workplace training survey research should be made.

- Consideration could be given to enlisting the STUC to co-ordinate consistent union activity in support of those with a diagnosis of dementia and /or that of their carers in Scotland.
- Tailoring of the dementia aware training intervention is needed to further support employers to make workplaces more dementia aware and to prompt sustained action within organisations over the medium to longer-term. In particular, consideration should be given to including tailored packages of support for senior directors, carers who are employees, middle management, supported by regular follow-up ‘action’ prompts to keep momentum, knowledge and progress going as well as monitored and supported.
- Consider how Age Scotland’s dementia aware training offer can be augmented by providing additional resourcing support packages to overcome internal and external barriers experienced by organisations.
- Conduct research into the HR and Senior Management-related corporate barriers experienced within large workforces when developing and implementing dementia aware policies.
- Compose practical guidance for managers about how to approach and deal with employee dementia diagnoses in light of equality legislation and workplace instances of dementia and caring for someone with dementia.
- Conduct research into how unions could work with HR and Senior Management within large workforces to uphold rights-based approaches and dementia aware policies in Scotland’s workplaces using collective bargaining approaches rather than voluntarism to make adherence to dementia equality policies more consistent. Examination of how this could be undertaken within equality law compliance within larger public sector workforces under Public Sector Equality Duties should be included.
- Consideration could be given to how Age Scotland’s future dementia aware interventions could be designed to develop action plans to support earlier diagnosis and interventions in the workplace.
- Augmentation of dementia aware policy in Scotland’s workplaces would be benefited by a carers network/blog/community administered by a neutral party, like Age Scotland or another organisation, that provides specific support for those in work whilst caring for someone with dementia.
- Consideration should be made to develop statutory CPD qualification/s for dementia aware training to maintain employee capabilities and level of dementia awareness overtime as well as retain knowledge levels and provide quality assurance. Particular emphasis should be placed on agencies in Scotland that are supplying contract care staff to those supporting people with a diagnosis of dementia and older people.
- Consideration should be taken to develop ‘standard’ dementia aware workplace policies that take into account performance management approaches to support employers to have a more consistent approach in Scotland. Especially because HR and Senior Management are seen as instrumental to implementing such approaches and policies when the capability to fulfil original job remit/objectives is questioned as employees experience early-stage or diagnoses of dementia and/or need adjustments as a result of caring for someone with dementia.

- Consideration of further research into adverse effects of dementia on women should be explored, particularly taking into account pension contributions, part-time working, maternity/child care and factors that influence the long-term mental and financial wellbeing of women in Scotland.
- Consideration should be given as to how employers in Scotland can be informed, supported and instructed to provide improved travel/public signage in public areas to reduce level of confusion for those with a diagnosis of dementia to provide everyday support for those with dementia to live well and more independently.
- Consideration of how to improve response rate for any future workplace training survey research should be made.

CHAPTER 8: EVALUATION TEAM CONTACT DETAILS

To ask questions and/or for more information contained within this report, or please contact the evaluation team:

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