

BREAST
CANCER
NOW The research
& care charity



ACTWELL PROJECT REPORT

November 2020

INTRODUCTION

In Scotland around 4,700 women are diagnosed with breast cancer each year. It is the most commonly diagnosed cancer in women in the UK and current predictions suggest the incidence of breast cancer is predicted to rise by 27% between 2008-12 and 2023-27 (1).

There are many factors implicated in the development of breast cancer including genetics, lifestyle and the environment. It is currently estimated that at least 23% of breast cancer cases could be prevented and are related to lifestyle behaviours including being overweight or obese, alcohol consumption and physical inactivity (2).

It is widely accepted that obesity is the biggest preventable cause of breast cancer and being overweight or obese after the menopause especially increases risk. Furthermore, the more weight you gain in your life, the higher your risk of developing breast cancer after the menopause. Evidence shows that you can help reduce your risk of developing breast cancer by being physically active on a regular basis. Regularly drinking alcohol also increases your risk of developing breast cancer. However, it is understood that many women are unaware of lifestyle issues in relation to risk of developing breast cancer (3).

In Scotland, the breast cancer community are exploring more innovative and sustainable preventative opportunities, including supporting weight management programmes. The need for weight management in Scotland is well set out in the Scottish Health Survey 2018. It reported 63% women in Scotland are overweight or obese - and this number increases with age with 72% of women aged 55-64 having a BMI >25 (4). In addition to this 38% of women in Scotland are not achieving the UK Chief Medical Officers (CMO) recommendations of 150 minutes of physical activity per week and this proportion increases with age.

Around 71% of Scottish women aged 50 to 70 years accept invitations to attend routine NHS breast screening programme with over 171,000 women being seen every year (5). Research suggests that women attending screening clinics are interested in receiving lifestyle advice (6) and research carried out by Breast Cancer Now highlighted the role of breast screening programmes as an opportunity for promoting cancer prevention activities (7). It is believed that attending screening offers a unique “teachable moment” for women to understand their risk of developing breast cancer and take action to help reduce that risk.

It is believed that partnerships between the NHS and voluntary sector organisations can offer value for money and potentially increase reach into local community settings and those from underrepresented communities. The approach of a community lifestyle intervention initiated in a breast screening setting has not been widely explored to date.

Project aim

ActWELL is a randomised control trial that aims to assess the effectiveness and cost-effectiveness of a theory based, community delivered, minimal contact, weight management (diet, physical activity and behaviour change techniques) programme in women with a BMI >25 kg/m² invited to attend routine breast cancer screening clinics.

Project overview

This study was delivered in four NHS areas across Scotland, Glasgow and Clyde, Grampian, Lothian and Tayside, using volunteer lifestyle coaches to deliver a lifestyle intervention to women, with no previous history of breast cancer, in the community. The intervention programme is a collaboration between Breast Cancer Now, the University of Dundee, NHS Scotland Breast Screening Programme (NHSBSP), leisure trusts and other academic institutions.

The University of Dundee led on the ActWELL study and have been responsible for the study design, research questions and for collecting and analysing all data relating to the trial. Their results will be reported back to the Scottish Government.

Breast Cancer Now supported the delivery of ActWELL by providing a team of volunteers, known as ‘lifestyle coaches’ to deliver the lifestyle intervention. Breast Cancer Now also coordinated and managed the intervention delivery across the 4 ActWELL sites. This is the first time a breast cancer charity has offered volunteer capacity for cancer prevention action on weight management via breast screening clinics. This offers significant potential to address gaps in public health efforts.

Objectives

- Develop and introduce organisational volunteer policies and procedures to support volunteers to deliver the intervention
- Recruit a team of volunteer lifestyle coaches to deliver the ActWELL intervention
- Provide appropriate training and support to allow volunteers to carry out their role
- Establish appropriate data handling processes for volunteer and participant data
- Co-ordinate and manage delivery of the intervention across four ActWELL sites
- Share key learnings on project set up, roll out and the deployment of volunteer lifestyle coaches to deliver the ActWELL project

Measuring the impact on ActWELL volunteer lifestyle coaches

Supplementary to this it was important for Breast Cancer Now to understand the motivations and experiences of the volunteers delivering ActWELL and what impact being involved in the project had on them.

Project Outcomes

- Lifestyle coaches feel confident and have the skills to deliver the ActWELL intervention to participants
- Lifestyle coaches feel supported and valued in their role
- Lifestyle coaches have an increased understanding and awareness of the link between lifestyle behaviours and breast cancer
- Lifestyle coaches make positive changes to their own lifestyle behaviours linked to reducing the risk of breast cancer (diet, weight, alcohol and physical activity)



METHODOLOGY

ActWELL is a weight management intervention designed to be delivered by volunteers. This involved two days of bespoke training to allow volunteers to deliver the intervention which consisted of two face to face intervention meetings (one of 60 minutes and one of 45 minutes) in leisure centres, followed by up to nine telephone contacts over a 12 month period.

The initial part of the intervention (months 1 to 3) focussed on weight loss and the remaining months combined techniques for weight loss maintenance by addressing both caloric intake and energy expenditure. The intervention used behavioural change techniques including personalised advice, motivational interviewing, goal setting, implementation intentions, self-monitoring of body weight and feedback.

The focus of the intervention was on sustainable lifestyle behaviour change (physical activity, diet and bodyweight). Lifestyle coaches agreed up to three goals with each participant during the face to face visits, one for physical activity, one on weight monitoring (self-weighing) and one on food/drink choices. All participants were given a caloric prescription this was based on a daily 600kcal deficit required for weight loss. The phone calls were used to support women to continue to maintain their goals for 12 months.

Project Set up

Volunteer Management

Breast Cancer Now were responsible for the recruitment of the volunteer lifestyle coaches to deliver the intervention. The trial team initially planned for 24 trained volunteers, six volunteers in each location. Breast Cancer Now provided a full-time member of staff, the ActWELL Project Officer, to manage the co-ordination and delivery element of the ActWELL trial, including recruiting, managing and deploying the team of lifestyle coaches.

Volunteer management processes

The ActWELL Project Officer initially reviewed the organisational volunteer policies and procedures. It was necessary to develop a volunteer policy and put in place associated volunteer processes and procedures that were appropriate for supporting the delivery of ActWELL, including:

- volunteer recruitment processes
- volunteer recruitment pack
- volunteer handbook
- volunteer agreements
- induction training
- data handling and confidentiality agreement
- volunteer exit feedback form.

An ActWELL Lifestyle Coach volunteer role description was developed with the trial team. This outlined the project and detailed the responsibilities, expectations and time commitment of the role.

Volunteer Recruitment

Advertising

Volunteer recruitment was carried out using an online application form hosted on Breast Cancer Now's website. This allowed for data from volunteer applications to be collected, transferred and stored securely to a supporter database. A variety of advertising methods were planned for each recruitment phase including press releases, Breast Cancer Now social media (Facebook and Twitter), stakeholder outreach (trial team and leisure trusts), requests to other organisations to share on their social media, case studies and external websites. For each recruitment phase the opportunity was also advertised in local volunteer centres in Edinburgh, Glasgow, Dundee and Aberdeen and on the Volunteer Scotland website.

Selection process

Recruitment of volunteers took place across all 4 ActWELL sites simultaneously. The ActWELL Project Officer and the trial team were responsible for selecting suitable applicants to take forward to training. Selection criteria was based on their application meeting the personal specification criteria of skill, in addition to location and availability.

The trial team placed importance on meeting suitable applicants in person to gauge their interpersonal skills and ability to interact with trial participants on a one to one basis. Where this was not an option a one to one phone call with the ActWELL Project Officer and a member of the trial team was deemed a suitable alternative. It was also essential that successful applicants could attend the two days of training, to travel to the participating leisure centres to meet participants, have access to a computer and have secure storage for storing personal data at home.

Data Handling

The ActWELL project required two distinct data handling processes:

1. Breast Cancer Now was responsible for collecting and processing the personal details of all applicants to the ActWELL volunteer lifestyle coach role.
2. The University of Dundee was responsible for collecting personal details on trial participants. Breast Cancer Now were required to receive and securely process the participant data and send it on to volunteers.

ActWELL Volunteer Data Flow diagram (Appendix 1) and ActWELL Participant Data Flow diagram (Appendix 2) were produced to outline how data was to be processed as part of the project. Data handling procedures were developed and revised as the project progressed to ensure compliance with changes to General Data Protection Regulation (GDPR) in May 2018.

A data sharing agreement was put in place between Breast Cancer Now and the University of Dundee, outlining each organisations responsibility for controlling and processing personal data. It was essential that each organisation was responsible for seeking appropriate permissions to share the personal data they collected, with the other organisation.

Breast Cancer Now collected volunteer personal data via an online application form hosted on their website. This included a privacy statement seeking appropriate permission to process personal data and contact volunteers in relation to the trial.

The trial team shared trial participant data with Breast Cancer Now via Box, a secure online file sharing platform.

Breast Cancer Now were responsible for sharing trial participant data with volunteers, this included participant name, contact telephone number and information relevant to the trial intervention. Due to the sensitive nature of the data it was important this was shared securely and volunteers were clear on their responsibility around data handling.

Initially participant data was sent via encrypted email. With support from the Breast Cancer Now's IT team, Microsoft SharePoint Online was then used for sharing personal data. This allowed the secure storage of documents which were required to be accessed and viewed from different locations by different users. This system is considered industry standard and has several different security features to help protect and secure documents saved online, including:

- restricted access to a limited number of users
- shared links only usable by the email address that links were sent to and
- only when that email address has logged in with their Microsoft account

To ensure volunteers were clear on personal responsibilities around data handling they received data protection training and a Confidentiality and Data Handling Procedure guidance document. Both were mandatory and a signature by each volunteer on their volunteer agreement was a declaration they understood the responsibility of the volunteering role.



Project Roll out

Training and Induction

ActWELL lifestyle coach training was developed and delivered by the University of Dundee, the University of Edinburgh and Breast Cancer Now. The training was designed to be delivered over two days and covered background to the trial, delivering the intervention, role play, completing trial paperwork and data protection. Pre-course reading was sent out to volunteers prior to the training days. To progress to taking on trial participants, lifestyle coaches were required to pass a multiple-choice exit test at the end of the training and provide signed evidence of two practice coaching sessions, with friends of family members, within three weeks of training and return to the trial team.

Following the training all volunteers were required to attend a Breast Cancer Now induction. In addition, the leisure trusts required volunteers to attend an induction at the leisure centres which included:

- a tour of the venues and introduction to staff
- health and safety procedures
- details on how to book meeting spaces and
- an overview of the leisure trust activity programmes.

Where possible group inductions were arranged, one induction session per ActWELL site, in one of the participating leisure centres. This allowed both the Breast Cancer Now and leisure trust inductions to take place on the same day. On some occasions it was necessary to organise bespoke inductions where volunteers were unable to attend the group induction.

Leisure Centres

Leisure centres supported the delivery of ActWELL by identifying and providing access to appropriate meeting spaces where the face to face meetings would take place.

Prior to the project commencing the ActWELL trial team had identified the leisure trusts operating within the four ActWELL geographic sites - Sport Aberdeen, Culture and Leisure Dundee, Edinburgh Leisure and Glasgow Life.

Each leisure trust identified a member of staff to liaise with the ActWELL Project Officer and suitable leisure centres to deliver the face to face visits. Suitable venue requirements included access to a private meeting space, good geographical spread across the city and be easily accessible for participants and volunteers. Each leisure trust developed a bespoke volunteer induction and booking procedures specific to their organisation's requirement.

Resources

As part of the induction, volunteers were provided with the resources required to deliver their role:



ActWELL participant bags - During their first visit participants were given the following:

- Pedometer
- ActWELL participant pack
- ActWELL Diet diary
- British Heart Foundation 'Facts Not Fads' booklet
- Food label traffic light card
- Breast Cancer Now's Touch Look Check (TLC) leaflet
- Cancer Research UK's Ten Top Tips
- Move More Leaflet

Weighing scales - all participants were offered a set of scales to take home if they did not have access to any.

Coach paperwork - to collect information on each participant for the trial team. Data Coach Record Form 1 (Data CRF 1) and Data Coach Record Form 2 (Data CRF 2) collected information to be used as trial data for reporting. The Coach Record Form allowed lifestyle coaches to record notes on each participant tracking progress during each contact. Pre-paid envelopes were provided for returning all paperwork and any travel expenses.

Mobile phone - all volunteers were provided with a contract mobile phone to contact trial participants, and to allow them to carry out the nine telephone calls as part of the intervention.

Secure storage box - volunteers who did not have secure storage at home (locked drawer/ filing cabinet) were provided with a lockable filing box to store all trial paperwork.

Participant Recruitment

Rolling recruitment took place over 14 months and began in NHS breast cancer screening units (static and mobile) from July 2017 to August 2018. Mammographers were trained to endorse ActWELL, highlighting the link between lifestyle and cancer risk during routine screening appointments. Women also received an information leaflet about ActWELL. Those interested in participating left their contact details on a post card in a sealed box. Research nurses randomly selected cards each week and screened women for eligibility before inviting them to attend a baseline appointment. At this point they were randomly allocated to the comparison group or intervention group.

Comparison group: received standard care with health information leaflet.

Intervention group: received the ActWELL intervention.

The target was to recruit 552 women in total to the trial.

Allocating participants

Each week the trial manager shared a list of intervention trial participants with Breast Cancer Now. The ActWELL Project Officer was responsible for matching and allocating participants to lifestyle coaches. At the outset, lifestyle coaches were asked to provide the days and times of the week that they were able to carry out the face to face visits and the leisure centres they were able to travel to. Matching participants to lifestyle coaches was based on the location of the participants in relation to leisure centres and their reported availability. As the trial progressed it was also based on each lifestyle coach's capacity to take on additional participants.

Lifestyle coaches would receive participant contact details and associated trial data via SharePoint. This was recorded on their Coach Record Form before the meeting. They were responsible for making contact with participants to arrange the time and venue of their first meeting and confirming the booking with the leisure centres. After the initial visit the lifestyle coach and participant arranged the next face to face visit and phone call dates at times convenient to them both.

Trial paperwork

During each visit or phone call with participants, the lifestyle coach was required to make notes on the Coach Record Form and record specific information relevant to the trial on the Data CRF. After the second visit volunteers were required to return Data CRF 1 to the trial team. This allowed the trial team to track participants who had begun

the intervention. After the final phone call Data CRF 2 and the Coach Record Form were returned directly to the trial team. The data from each of the Data CRF's were used as part of the study data analysis and Coach Record Forms were tracked and destroyed by the trial team for data protection purposes.

Comparison Group visits

On completing 12 months in the study, all comparison group participants were offered a one-off coaching session with a volunteer lifestyle coach. The process described above for the intervention group in terms of allocating and contacting participants was followed for the comparison group also. However, lifestyle coaches were only required to arrange one face to face visit, with no follow up, and complete and return a Coach Record Form for the trial team.

Volunteer support and management

A variety of methods were used to provide ongoing support to volunteers throughout their involvement in the project.

Support calls and emails - on completing the first visit with a participant the ActWELL Project Officer arranged to call them. This was to check how their first visit went, highlight any issues with the venue, participant or any elements of the intervention after they had experience of delivering it. Throughout the trial the ActWELL Project Officer maintained regular email and phone contact with all lifestyle coaches, the method varied depending on individual preference.

Frequently asked questions document - Breast Cancer Now and the trial team put together a 'frequently asked questions' (FAQ) document based on common queries relating to participants, paperwork and issues arising as the trial progressed. This was updated regularly and sent to all lifestyle coaches by email.

ActWELL Newsletter - a bi-monthly newsletter was sent out to all lifestyle coaches updating them on the trial progress, introducing members of the trial team, highlighting relevant news from Breast Cancer Now and regular reminders.

Group Support - regular group support sessions in each of the 4 ActWELL areas took place approximately every 3-4 months. These sessions were not mandatory but provided an opportunity for volunteers to come together and share experiences and offer each other support. It also allowed the ActWELL Project Officer to highlight experiences of coaches from other areas, provide an update on the progress of the trial to date and allocate more ActWELL resources to those who needed them. These sessions took place in a variety of locations (a mixture of pro bono and

paid for venues) including participating leisure centres, Aberdeen University, other voluntary organisations meeting rooms, and the Maggie's Centre in Dundee.

ActWELL Celebration event - in March 2019 Breast Cancer Now organised a celebration event to bring together all the volunteers, the trial team and Breast Cancer Now staff. This provided an opportunity to say thank you to the volunteers and for:

- volunteers from each of the areas to meet up again and share their experiences across the four ActWELL sites
- the trial team to give an update of the trials progress to date
- Breast Cancer Now to carry out some evaluation through feedback from coaches on their experiences to date via written feedback, photography and some short videos.

Other methods of recognition - following one year of a volunteer's involvement in the project they were sent a thank you card signed by Delyth Morgan the CEO of Breast Cancer Now. As part of Volunteers Week 2019 a series of social media posts were shared of individual case studies and a blog was written for the Breast Cancer Now website 'Celebrating the positive impact of volunteering' which showcased a selection of the lifestyle coaches and their experiences of volunteering.

Exit interviews - when the lifestyle coach role came to an end each volunteer received a final exit interview with the ActWELL Project Officer, where possible in person, but otherwise as a telephone call. Following this they were emailed a link to a volunteer feedback form.



RESULTS: MONITORING AND ANALYSIS OF ACTWELL PROJECT DATA

Volunteer Recruitment

Advertising

In total Breast Cancer Now carried out four rounds of volunteer recruitment between May 2017 and August 2018. Advertising in May 2017 and January 2018 was Scotland-wide and set out to reach and engage applicants across the four ActWELL sites. Advertising in July 2017 and July 2018 was targeted geographically to address specific gaps and address capacity issues.

Round 1

The first recruitment campaign for ActWELL lifestyle coaches formally launched on 2 May 2017 with a media release - written by Breast Cancer Now and distributed by the Scottish Government. This media release resulted in 60 pieces of coverage including an article on the BBC news website and radio broadcast.

Social media activity, Twitter and Facebook, commenced prior to this media release. However due to an unprecedented response to the campaign no further social media activity took place. With the exception of stakeholders directly involved in the trial (Scottish Cancer Prevention Network (SCPN), universities and leisure trusts) and local volunteer centres, no stakeholder outreach activity took place at this point as it was not required.

Round 2

A second round of recruitment took place in July 2017. Additional training was arranged due to drop out of volunteers in some areas and also recognising the capacity of volunteers may not be as high as the trial team initially anticipated. The focus was on recruiting additional coaches in Dundee and Aberdeen for training days in September 2017. This was driven by social media with two promoted paid for Facebook posts in July 2017 resulting in a combined reach of 11,048.

Social media was supplemented with stakeholder liaison activity by creating suggested social media content and copy for online and newsletters that could be used to promote the role. This information was disseminated to local authorities, local sports organisations, NHS organisations, Universities and relevant voluntary organisations in Aberdeen and Dundee. In total, 13 organisations in Aberdeen and eight in Dundee were contacted and agreed to use the information that was provided.

Round 3

The third round of recruitment took place in January 2018. The challenge for this was not to create a high volume of applications but to find the right people who could commit to the role until the end of the trial. The focus was on a series of local media releases which drew on the experiences of existing Lifestyle Coaches. A different case study from each area was used. This approach was replicated across social media with case study quotes and pictures used to promote the recruitment drive. A promoted post on Facebook on a general recruitment call out was also used. Once again, social media content and copy was created for organisations to use. 13 organisations in Aberdeen, eight in Dundee, 18 in Glasgow and 12 in Edinburgh were contacted.

Round 4

The final recruitment drive was for telephone coaches therefore volunteer location was less of an issue. Media focus was on Edinburgh, Lothians, Fife, Forth Valley, Perth, Dundee and Tayside. Again a promoted Facebook post was used to target the message.

Social media reach

Between 7 April 2017 and 20 July 2018 Breast Cancer Now (Scotland) social media accounts posted 21 tweets and 16 Facebook posts to advertise the post.

Total Twitter impressions **23,716**

Total Facebook reach **66,985**

Two of the most popular Twitter posts were using recruitment quotes from ActWELL lifestyle coaches in Dundee and Aberdeen for round 3 of recruitment in January 2018, receiving 2,972 and 5,092 impressions respectively.

The most popular Facebook post was the promoted post in round 3 of recruitment creating a total reach of 32,545 and 63 shares.

Applications

In total 170 applications were received between May 2017 and September 2018. Round 1 received the highest number of applications, with 101 in total (Figure 1) which is likely to be as a direct result of the interest gained from the Scottish Government media release being picked up by media.

Round 2 received the least applications, however this was focussed on recruiting volunteers in specific areas (Dundee and Aberdeen) where there had been less applications in round 1. In Glasgow and Edinburgh there were applicants from the first round of recruitment who were taken forward for training in September 2017, so further recruitment in those areas was not required.

Figure 1: Number of applications by recruitment round

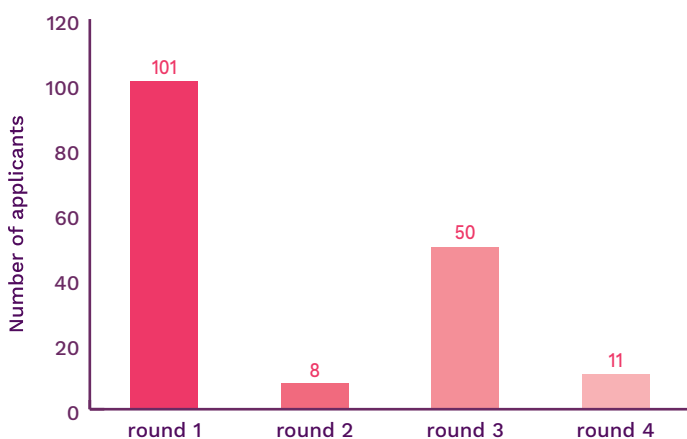
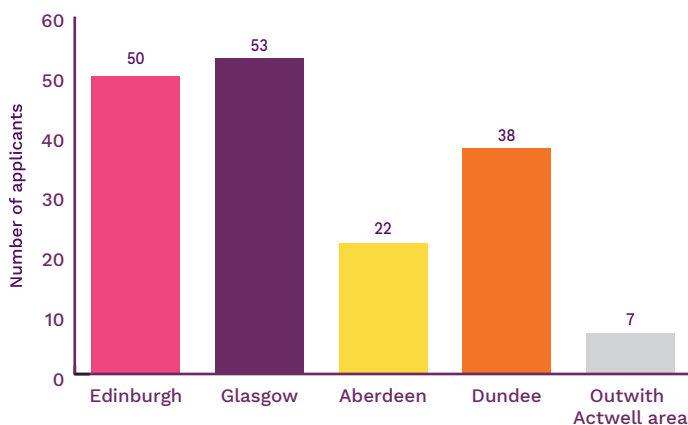


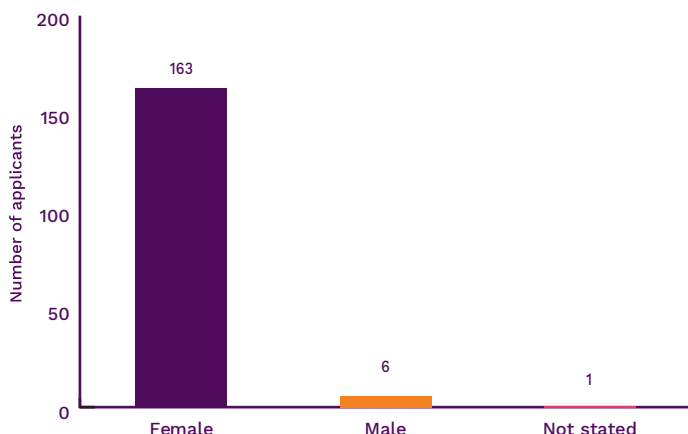
Figure 2 shows that most applications came from Edinburgh and Glasgow, 50 and 53 respectively. As these are the larger cities this was expected. Aberdeen had the lowest number of applicants. Applicants were categorised as ‘Outwith ActWELL area’ if it was deemed there would be significant travel to a leisure centre from their home address (over 30 miles). This included two applications from individuals based in England who were interested in the project and one applicant requested an international placement as part of a university course from Italy. The lifestyle telephone coach role could be delivered anywhere in Scotland and accounts for some of the other applicants in this category.

Figure 2: Number of applications by area



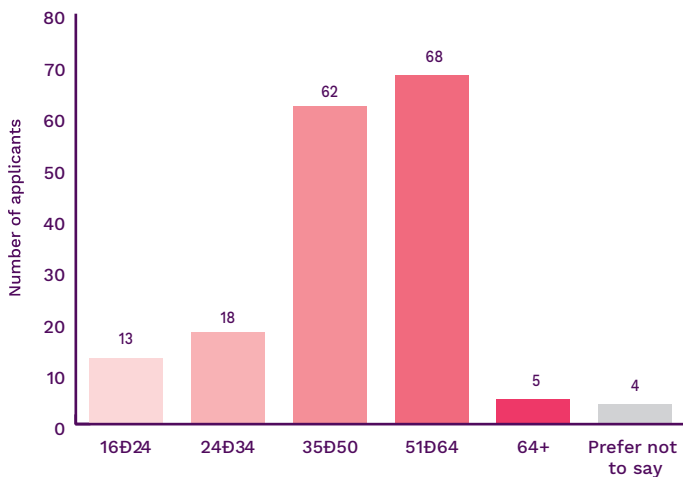
Data was captured on gender, age and ethnicity of applicants. Given the project was delivering a behaviour change lifestyle intervention to women it wasn't surprising that applications predominantly came from women, in total 163 applicants identified as female (Figure 3). However Scottish Household Survey 2017 data also highlights that women are more likely to volunteer than men, so this is consistent with Scottish volunteering data (8). No decision was taken to exclusively recruit women and in total six applications were received from men.

Figure 3: Number of applications by gender



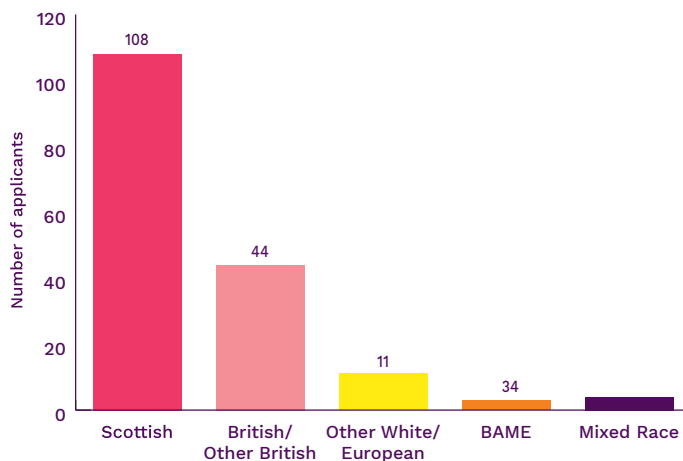
The role had the greatest appeal to women aged 35 and over. In total 79% applicants were over 35, with the highest number of applications (68) coming from the 51-64 age group. Again, given the nature of the role, delivering an intervention to women between 50-70 as well as the skills and experience required for the role, this was expected.

Figure 4: Number of applications by age



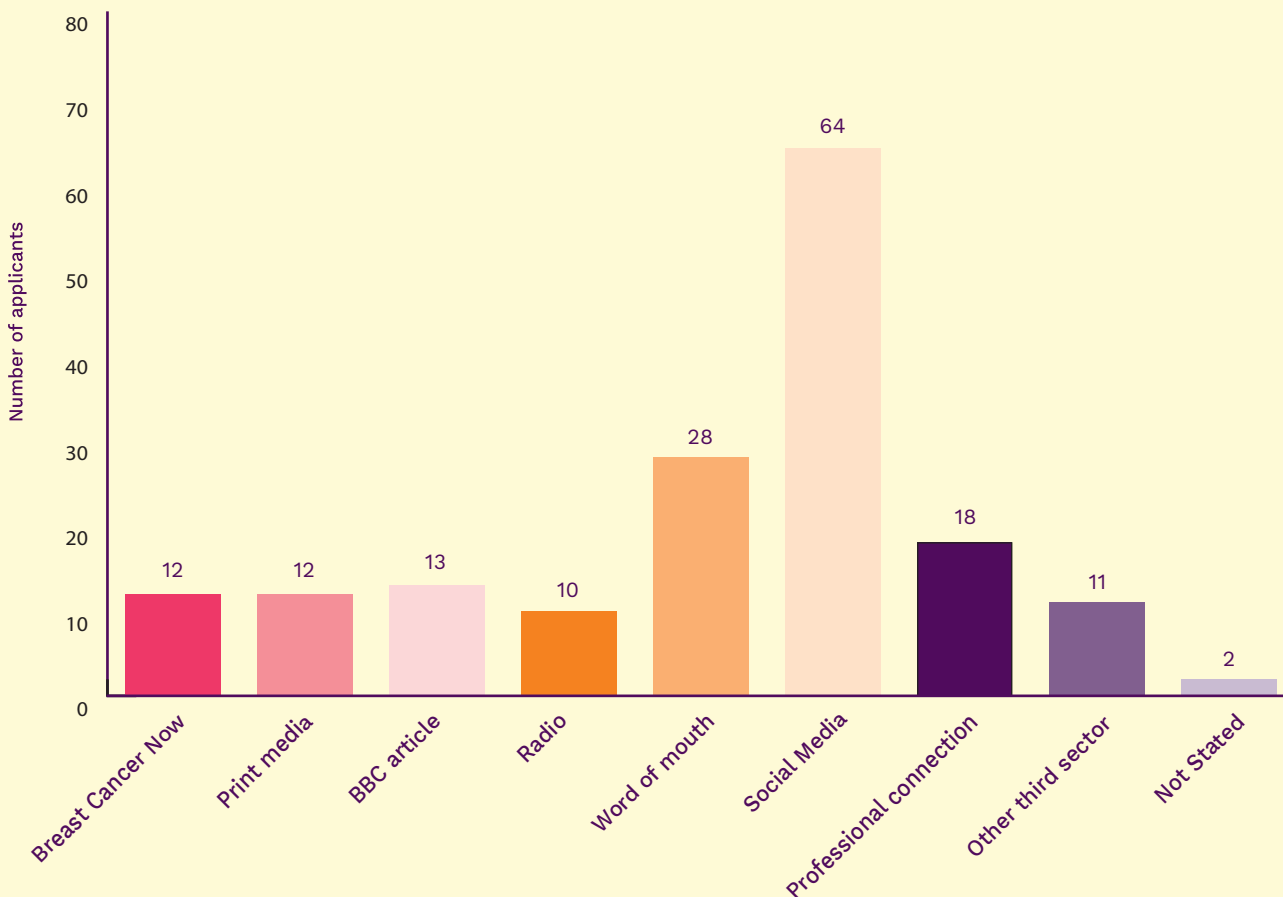
In total 96% of applicants identified as White, with 63% identifying as White Scottish. The total identifying as non-White ethnic was 4% which is reflective of the Scottish population, although slightly lower than in the four cities recruitment took place in (9).

Figure 5: Number of applicants by ethnicity



Applicants were asked how they had heard about the lifestyle coach volunteering opportunity, this is summarised in figure 6. The most commonly cited method was via social media (38%), followed by word of mouth (16%) and through professional connections (11%). The BBC article alone was cited by 8% of applicants which highlights the reach this had in round 1 of recruitment. This data demonstrates the value of using social media and social networks for volunteer recruitment.

Figure 6: How applicants heard about this opportunity



Volunteer selection

The initial plan was to follow up with applicants informally by phone before making decisions on who to invite for interview. Due to the high volume of applications, short timescales, geographic spread and simultaneously recruitment across four cities the selection process was revised. Depending on the round of recruitment, interviews were either group selection sessions, individual face-to-face or telephone interviews. Throughout the selection process applications were categorised as follows:

Application approved and invited to interview	Any applicant whose application met the criteria and was invited to interview or selection session
Applicant withdrew	Any applicant who was invited to interview but withdrew application before/after interview
Application rejected	Applicant not appropriate for role based on location, lack of experience or skills in relevant area, availability or conflict of interest
Application approved	Any applicant who had appropriate skills and experience but wasn't invited to interview; mainly, they were not available for interview and/or training dates

126 of the applicants were assessed as suitable for interview based on the selection criteria. Of these, 114 were interviewed either through a selection session, face to face interview or telephone interview which was 66% of applicants. In total 73% of applications were approved and applicants were viewed as having the skills and experience to carry out the role. This suggests that the role description and volunteer information pack was pitched at the right level in attracting the calibre of applicant required for the role. 12 applicants withdrew their application following an invite for interview and this was mainly a result of being unable to attend the training dates, no longer being interested in the role or their commitments had changed.

Of the six male applicants three were assessed as suitable and invited to a selection session. Two were then invited to attend one of the training dates. Both declined the invitation, one due to personal commitments on the training dates and the other as the role was not what he expected.

Summary of recruitment by round

May 2017 Recruitment

Due to the high volume of applications group selection sessions were organised in each of the four ActWELL areas. All suitable applicants were invited to attend a selection session, Table 1 details numbers attending each session according to area.

Table 1: May 2017 selection session attendees

LOCATION AND VENUE	ATTENDEES
Aberdeen , University of Aberdeen	8
Edinburgh , Royal Commonwealth Pool	14
Glasgow, Mitchell Library	16
Dundee, Ninewells Hospital	15

At each selection session three staff involved in the project were present: the ActWELL Project Officer along with staff from the trial team and where necessary an additional member of staff from Breast Cancer Now.

Suitable candidates were invited to attend the ActWELL training dates in June 2017. Not all invitations were accepted and some candidates withdrew while others were unavailable for the training dates. Those unable to attend training in June 2017 were automatically invited to future training.

September 2017 Recruitment

This was a much smaller and targeted recruitment process with advertising focussing on Dundee and Aberdeen. In Glasgow and Edinburgh suitable applicants from the previous selection sessions were invited to attend training. Also, suitable applicants from the previous round of recruitment who had been unable to attend the selection sessions were followed up for interview.

All applications were assessed for eligibility by the ActWELL Project Officer and the trial team. No selection sessions took place this time and where possible face to face meetings with volunteers were arranged to coincide with delivering inductions for the first wave of volunteers.

- 10 phone interviews with new applicants in August 2017
- 4 face to face interviews with applicants from May 2017

January 2018 Recruitment

The approach to recruitment in round 1 was taken. Suitable applicants were invited to attend a selection session in one of the ActWELL areas. Where an applicant was unable to attend the ActWELL Project Officer arranged a face to face meeting. Previous applicants were also contacted to gauge interest and followed up.

Table 2: January 2018 selection session attendees

LOCATION	ATTENDEES
Aberdeen, University of Aberdeen	7
Edinburgh, Royal Commonwealth Pool	8
Glasgow, Kelvinhall Leisure Centre	13
Dundee, Ninewells Hospital	6

- 2 phone interviews with applicants from January 2018
- 1 individual attended February training as work placement as a medical student and applied retrospectively

August 2018 Recruitment (telephone coaches)

A final round of recruitment took place for telephone only coaches in July 2018. This was to address capacity issues and ensure all participants were seen by a lifestyle coach. Again, all applications were checked for suitability and previous selection session attendees were contacted to find out if they were interested in the role. The ActWELL Project Officer then carried out telephone interviews with all applicants.

- 11 phone interviews with applicants from July 2018
- 2 phone interviews with applicants from January 2018

Training and retention

In total 66 volunteers were trained to deliver the ActWELL intervention. 57 attended one of the two day ActWELL Lifestyle Coach training and 9 attended the one day ActWELL lifestyle telephone coach training and 45 went on to actively take on trial participants.

Table 3: Summary applicants progression

STAGE OF THE PROCESS	NUMBERS
Applied to be a volunteer Lifestyle Coach	170
Interviewed	114
Trained	66
Active Lifestyle Coach	45

The training was delivered in a central location over two days and was designed to ensure that lifestyle coaches could deliver the trial protocol with confidence. The training days evolved at each training session based on the feedback from volunteers. For example, the following suggestions were made and acted upon:

- More opportunities to role play and practice delivering the intervention with peers
- Observe role play of a session being delivered
- More time spent on how to deliver the intervention and complete paperwork with less time on theory and background to the study.

Volunteers commented on there being a lot of information to take in and feeling overwhelmed by the end of the two days. Poor weather conditions forced the second training day in February 2018 to be abandoned early and a second day was rearranged a few weeks later. Volunteers commented this was beneficial as it allowed them to reflect on the first day, practice delivering the face to face sessions and come back prepared with questions.

Volunteer drop off after training is always expected. In total 21 of those trained did not continue to become a lifestyle coach or dropped out soon after commencing their role and the reasons for drop out are listed below in Table 4. Changes to personal circumstances i.e. moving home, changing job or family caring responsibilities, were common and are typical of any volunteering role. Where there are changes to personal circumstances volunteering is usually the priority given up.

Table 4: Volunteer reasons for leaving

REASON FOR LEAVING	NUMBERS
Moving Home	2
Personal Circumstances	4
Increase in work commitments	3
Role not what I expected	3
Not getting what I wanted from role	1
Lost contact	2
Mutually agreed - not suitable	2
Did not complete training	2
Long delay before commencing role	2
Total	21

Volunteer retention was lowest after the first round of training. Table 5 shows that just over half (54%) continued to actively take on participants. This can be attributed to some finding the role become too big a commitment and not what they had expected. Some fed back that the amount of paperwork and length of commitment was more than anticipated leaving them feeling overwhelmed and that they no longer felt able to commit. However, this was exacerbated by a delay in participant recruitment in Edinburgh until November 2017. This resulted in coaches waiting for five months between training and taking on trial participants. By this time some had lost interest and others had taken on other commitments and felt they no longer had the same capacity as when they had initially applied to the role.

Table 5: volunteer retention by training date

TRAINING DATE	NUMBERS TRAINED	DROP OUT	RETENTION
June 2017	26	12	54%
Sept 2017	13	4	70%
February 2018	18	2	88%
July 2018	9	3	67%
Total	66	21	68%

In subsequent recruitment rounds the role information was revised and during the selection process the expectations and commitment of the lifestyle coaching role was made clearer. Case studies of lifestyle coaches' experiences were produced during recruitment to highlight the benefits of the role which also helped with a targeted approach to recruitment and cut down on unsuitable applications.

One volunteer left because she felt she was not getting what she wanted from the role. This was a result of the discrepancy in where participants were being recruited in relation to her availability to meet them at a leisure centre. She was only able to arrange a visit and take on one participant and as a result left the role. On completing the training some volunteers lost touch or did not complete the practice sessions and progress to taking on trial participants. Following the training, two individuals agreed with the trial team they were not suitable to carry out the role

Of the 45 lifestyle coaches who actively took on participants, 10 were based in Aberdeen, 10 in Dundee, 8 in Edinburgh, 11 in Glasgow and 6 were lifestyle telephone coaches.

ActWELL Intervention delivery

Participant recruitment

Participant recruitment and trial data collection was the responsibility of the research nurses and the trial team. Table 6 provides summary data on participant recruitment and retention which was made available to Breast Cancer Now from the trial team.

Table 6: Summary data on participant recruitment in each ActWELL site

	NUMBER INTERESTED	NUMBER RECRUITED	INTERVENTION GROUP	COMPARISON GROUP
Aberdeen	1,366	151	74	77
Dundee	1,066	148	75	73
Edinburgh	630	144	72	73
Glasgow	650	116	58	58
Total	3,712	560	279	281

In total 3,712 women registered their interest in taking part in the trial and 560 participants were recruited to the trial, this was slightly higher than the overall target of 552. Participant recruitment was not equal across the four ActWELL sites, the explanations for this are described elsewhere by the trial team. This resulted in three areas recruiting more participants than initially planned and which had an impact on the capacity of lifestyle coaches in some areas towards the end of the recruitment phase.

In total 467 participants attended the final visit with the research nurse and completed the trial.

Allocating participants to volunteers

Table 7 summarises the contact between lifestyle coaches and participants. A total of 279 intervention and 100 comparison participants were supported by lifestyle coaches. Overall lifestyle coaches delivered a total of 623 face to face coaching sessions (523 to intervention and 100 to comparison participants) and made approximately 1,915 telephone calls over the year, comparison participants only received a face to face visit and no telephone contact.

Table7: Summary of contact between lifestyle coaches and participants

	INTERVENTION	COMPARISON
Total number of face to face coaching sessions	523	100
Total number of telephone support calls	1,915	-
Average number of participants per Coach	7	6
Maximum number of participants supported	15	15
Minimum number of participants supported	3	1

Intervention Group

In total 39 volunteers took on intervention participants for a face to face visit and six took on participants for telephone calls only.

The number of intervention participants' lifestyle coaches took on ranged from three to 15, with the average number of participants supported being seven. This was significantly lower than the numbers of participants the trial team had initially expected each volunteer to support (estimated between 12-14 participants per lifestyle coach). Over a quarter of the coaches, 11 in total, supported 10 or more intervention participants with face to face visits.

The number of participants supported varied between lifestyle coaches and it was influenced by their ability to juggle visits and phone calls as part of their weekly routines. Factors such as availability, work, family and personal commitments, employment status, retirement, changes to personal circumstances and their own enjoyment contributed to their capacity in taking on participants. This was exacerbated by the timeline set out in the lifestyle intervention protocol where all participants had to receive their first visit with a coach within four weeks of their baseline visit with a research nurse. Other issues impacting on capacity to take on participants are detailed in table 8.

In September 2018, a revised role was developed, the telephone lifestyle coach, to ensure all participants received the full intervention. Lifestyle coaches initially took on participants for the two face to face visits and the first phone call, after this their details were passed to a telephone lifestyle coach to deliver eight phone calls for the remainder of the trial. This approach freed up the capacity of the lifestyle coaches allowing them to continue taking on participants for face to face visits. Time constraints and the deadline for delivering the trial prevented further lifestyle coaches being trained at this time. In total 14 participants were reallocated to a telephone coach after they received the face to face visits with a lifestyle coach.

Table 8: Issues impacting lifestyle coaches' capacity to take on participants

Cancelled visits	Participants cancelling visits or not turning up to an appointment had an impact on a lifestyle coach's availability where rescheduling meetings was necessary. This often resulted in them being unable to take on another participant until the rescheduled visit had been made.
Location of leisure centres	<p>Lifestyle coaches identified the leisure centres they could travel to for the face to face visits and the ActWELL Project Officer matched them to participants that were recruited in that area. Participants were recruited centrally by research nurses, so the spread of participant recruitment was not always equal across all leisure centre sites.</p> <p>In Edinburgh and Glasgow, there were times where participants were recruited in one area resulting in some lifestyle coaches being relied on for allocating participants while others had periods of time where no participants were allocated to them.</p> <p>In Aberdeen there was only one leisure centre for visits to take place and in Dundee most coaches were able to travel to all leisure centres.</p>
Availability of lifestyle coaches	<p>Those who were in work were usually unable to commit to arranging visits on week days and were usually only available in the evenings or at weekends.</p> <p>Those with childcare commitments were often restricted to being available during the school day or weekends only. During school holidays, some were unable to commit to face to face visits with participants, this was particularly difficult over the summer holidays where some lifestyle coaches were unavailable to take on participants for 6-8 weeks.</p> <p>Those who were retired often took longer holidays, up to four weeks at a time, and this required them to plan and fit in visits with participants when they were available.</p> <p>The Christmas period was a challenge for most as other commitments and social occasions were prioritised. Lifestyle coaches reported participants were unwilling to arrange a first visit before Christmas and requested it was put off until January.</p> <p>Those with caring or other volunteering commitments were required to fit the meetings around these.</p>
Availability of participants	Some participants took long or frequent holidays, and several were away for up to three months. Others had a busy work life balance and had not realised the time commitment to participate in the trial. This often led to lifestyle coaches having to be flexible in their approach and in some instances the participant did not receive all the contacts the trial team aimed for.

Overall most lifestyle coaches felt they had taken on a manageable number of participants. Throughout the project they were conscious of their limits and would let the ActWELL Project Officer know when they had reached capacity in taking participants on. Most demonstrated flexibility when it came to arranging visits and could schedule the first visit within two weeks of receiving the participants' contact details. The main limitations to this were coach or participant illness, holidays around the time of allocations, participants' time commitments and availability, being unable to find a mutually agreeable time or difficulties in making contact initially. Some lifestyle coaches allocated dedicated days and times during the week to focus on ActWELL which allowed them to manage their own time and managed the expectations of participants in terms of their availability.

Where a lifestyle coach was unable to arrange a visit with a participant the ActWELL Project Officer was required to reallocate the participant to another lifestyle coach. This caused capacity issues if several participants were allocated at one time and other lifestyle coaches had already confirmed appointments with their participants making them unavailable to take on more participants at that time.

Volunteering as an ActWELL lifestyle coach was a significant commitment to make over a period of at least 14 months. Changes in personal circumstances were inevitable and it was anticipated that some would leave their role before the end of the trial period. However, in general when circumstances changed and a lifestyle coach was unable to continue taking on additional participants, they would agree to

continue supporting these participants until they had completed the trial. This highlighted the commitment lifestyle coaches had to the project and ensuring it was a success. There were only four occasions where changes in circumstances resulted in a lifestyle coach fully leaving their role and participants being reallocated.

Comparison group

All comparison group participants were offered a one-off lifestyle coaching session with a lifestyle coach on completing their 12 months in the trial. In total 108 comparison participants requested a lifestyle coaching session, table 9 summarises the requests by area. 17 lifestyle coaches agreed to take on comparison participants across the four ActWELL sites and the actual number of visits that took place was 99. Reasons for the other nine not taking place included participants were no longer interested when contact was made, cancelled the visit or did not attend.

Table 9: Number of comparison participant requests by area

AREA	NUMBER OF REQUESTS
Aberdeen	34
Dundee	24
Edinburgh	36
Glasgow	14
Total	108

Lifestyle coaches supported an average of six comparison group participants (see table 7). In Aberdeen and Dundee there was an even spread of participant requests in relation to the number of lifestyle coaches available to take them on. Edinburgh received the highest number of requests for a lifestyle coaching session, however only three lifestyle coaches were available. In Glasgow five lifestyle coaches were available to meet participants however only 14 requests came through. This accounts for the skewed maximum and minimum number of participants supported by each lifestyle coach, for example in Edinburgh lifestyle coaches were required to take more participants on, however in Glasgow some lifestyle coaches were only able to support one comparison participant. In Edinburgh demand was so great that a Dundee lifestyle coach arranged visits with four Edinburgh participants.

Lifestyle coaches frequently commented that face to face visits were the most enjoyable element of the intervention and they missed this when moving on to the support phone calls. They all enjoyed delivering these visits and felt the participants appreciated the support they received. Most lifestyle coaches would have been happy to continue and take on more comparison participants if there had been an opportunity to do so.

Volunteer support

There was support available to the lifestyle coaches throughout the project. They were required to attend a Breast Cancer Now induction, providing them with an overview of the charity's work and setting out what they should expect from the organisation.

A 'frequently asked questions' document was developed and regularly updated based on common questions and issues raised to the ActWELL Project Officer and trial manager. This was sent out regularly by Breast Cancer Now.

Throughout the trial lifestyle coaches were supported by Breast Cancer Now and the ActWELL trial team with regular phone calls and emails to address ongoing queries. In addition to this 12 group support sessions were organised, three in each of the ActWELL delivery sites, and a one off 'Celebration Event' was organised in Dundee which all lifestyle coaches were invited to attend. These provided opportunities for volunteers to come together to receive updates on the trials progress, offer peer support, share their experiences of being involved in the project, and discuss common issues and strategies they developed to overcome these.

Between June 2018 and September 2019 Breast Cancer Now produced and distributed seven ActWELL newsletters, updates on the ActWELL project, Breast Cancer Now and news related to their role. All lifestyle coaches received a 'Thank You' card from Breast Cancer Now when they reached their one year anniversary of being involved in the project.

Leisure centres

In total 12 leisure centres provided meeting spaces for the face to face sessions to take place across the four ActWELL delivery sites, the leisure centres used are listed in table 10. In each city, except Aberdeen, the aim was to have equal geographical spread to ensure participants would have a leisure centre option local to them.

Table 10: Leisure Centres providing meeting space by Leisure Trust

Sport Aberdeen	The Beach Leisure Centre, Linx Ice Arena
Culture and Leisure Dundee	The DISC, Lynch Sport Centre, Douglas Sports Centre
Edinburgh Leisure	Royal Commonwealth Pool, Ainslie Park Leisure Centre, Dumbrae Leisure Centre, Gracemount Leisure Centre
Glasgow Life	Glasgow Club Pollock, Glasgow Club Kelvinhall, Emirates Arena

Lifestyle coaches agreed that the leisure centres served a purpose and understood the rationale for using these venues, to engage with women in a space promoting physical activity. However most felt they could have met participants in any community venue that provided a meeting space.

There was consensus across all sites that leisure centre staff could not be faulted, and that staff were welcoming, helpful and supportive of the project. Where any issues occurred, reception staff would ensure they did their best to resolve them. Feedback on individual venues and meeting spaces was mixed and some issues raised with using the leisure centres are detailed in table 11. If the project was to be rolled out the practicalities of using leisure centres as a meeting space would need to be considered.

Successes, challenges and issues relating to delivering ActWELL

Lifestyle coaches suggested that the role being delivered by volunteers, rather than paid healthcare professionals, may have contributed to the success of the project. Those who became active lifestyle coaches demonstrated a great deal of enthusiasm and commitment to the ActWELL project. Some regularly went above and beyond

their role to keep participants engaged at times; following up missed calls and with participants who they lost contact with. They also showed flexibility when arranging visits and calls to suit the participants to ensure they remained committed to the trial. Some lifestyle coaches believed that participants placed higher value on their time as a volunteer, resulting in increased motivation and commitment to:

- remain engaged in the trial
- satisfy the lifestyle coach because they were giving up their time to provide support.

Throughout the trial lifestyle coaches highlighted various issues and challenges they faced around delivering the intervention, resources and supporting participants which are summarised in Table 11. These were mainly dealt with by the ActWELL Project Officer. Many issues were easily resolved and contributed to the ActWELL 'frequently asked questions' document. However, some issues arising were more complex, requiring significant staff time from other teams within Breast Cancer Now. This highlights the importance and necessity of having dedicated staff to support volunteers in the delivery of an intervention like ActWELL.



Table 11: Issues reported by lifestyle coaches relating to intervention delivery

LEISURE CENTRES	
Lack of suitable meeting spaces	<p>Leisure centres had limited meeting space. This restricted the venues that were made available to deliver the intervention.</p> <p>Some venues had no private meeting spaces and were only able to offer activity rooms or café space which could not be booked.</p>
Leisure centre staff awareness of ActWELL	<p>Some leisure centres had high staff turnover on reception, as a result staff were not always aware of the ActWELL project or the role of the lifestyle coaches. This often led to volunteers spending time explaining the project before being given access to rooms.</p>
Losing access to meeting spaces	<p>Over the duration of the trial, access to meeting spaces was lost in some venues, at very short notice, with no alternative space given.</p> <p>Lifestyle coaches were unable to access a venue due to the European Championships as the site was being used as a venue for 2 months.</p> <p>In some leisure centres access to meeting spaces was limited during school holidays.</p>
Inappropriate venues and meeting space	<p>Location of some leisure centres in perceived unsafe areas led to concerns around safety for walk and talks, particularly in the winter when it was dark from late afternoon.</p> <p>Meeting spaces and locations within the leisure centres not always deemed appropriate for example:</p> <ul style="list-style-type: none"> • A balcony space next to a gym hall was provided in one venue with a curtain offering minimal privacy and protection from noise. • One meeting space required walking through an activity hall which was often in use. • One private meeting space was reported to be dingy and unwelcoming. • A crèche was being used in one location, which was private but felt to be unconventional. <p>On occasions where no meeting space was available lifestyle coaches were required to meet in cafés.</p> <p>Some duty managers could offer their office for an hour; however this would not be suitable if the project was rolled out.</p>
Booking rooms	<p>In some leisure centres lifestyle coaches were unable to contact staff by phone to book meeting spaces resulting in wasted time, frustration and requiring the ActWELL project officer to intervene.</p>
Key contacts in leisure centre staff moving on	<p>Key staff contacts moving on from their role in the leisure centres during the trial period often led to delays in resolving room access issues and receiving important updates on room access</p>
Participants travelling to leisure centres.	<p>Some participants were unwilling to travel to a leisure centre due to location in relation to travel time, distance from home and public transport links.</p> <p>Anecdotally there seemed to be an expectation from some participants that they would be able to attend any leisure centres in their area.</p> <p>It was noted that some participants, recruited from rural areas, were required to travel over 30 miles to attend a participating leisure centre.</p>
DELIVERING THE LIFESTYLE INTERVENTION	
Availability of water	<p>In certain leisure centres it was not practical for lifestyle coaches to access water for participants, which was part of the intervention visit 1. Lifestyle coaches often commented that it added additional time to the visit and interrupted the flow of the session.</p>

Walk and talk	In some leisure centres the process for locking and unlocking meeting rooms to carry out the walk and talk was an issue. This was also a problem where volunteers were required to use a café or open space that they were unable to reserve as tables were often occupied when they returned.
Time allowed for face to face visits	Lifestyle coaches often struggled to keep the visits to the allocated time, particularly visit 1. They believed building rapport was important during the first session, but the protocol didn't allow this time. They also reported that getting ready for the walk and talk, getting water following the walk and talk and the participants asking questions also contributed to this.
Losing contact with participants	Lifestyle coaches became demotivated when participants were difficult to contact or stopped answering their calls. When moving to phone calls some lifestyle coaches commented on their frustrations at dedicating time to make calls and the participants would cancel or rearrange at short notice or not answer.
Other health issues, queries and questions from participants	Lifestyle coaches were often asked questions or for advice that went beyond their remit of providing advice around lifestyle behaviour change. Many participants developed health issues (injuries, non-cancer diagnosis, mental health) during the 12 months in the trial which impacted on their perceived ability to adhere to the trial intervention. Some coaches struggled with the expectations of participants and the boundaries of the role, particularly in relation to support around mental health, relationships, bereavement and social isolation.

COACH RESOURCES

Coach paperwork	Some found the trial paperwork time consuming and more than they had anticipated for a volunteering role. The coach pack covered a lot of information and some commented that their coach pack page numbers didn't correspond with the participants pack often causing confusion referring to specific topics. There was some initial confusion over the timings for returning the different coach record which led to delays in paperwork being returned to the trial team.
Mobile phones	Mobile phones were the most common issue raised as part of the trial and lifestyle coaches found them difficult to use. They had limited storage for text messages, some stopped working or had battery issues. They were difficult to use and sending texts as reminders for visits and calls was time consuming. Some lifestyle coaches resorted to using their personal mobile phones. This required Breast Cancer Now to intervene and develop guidance on using your personal device to comply with GDPR regulations.
ActWELL participant packs	Storing ActWELL participant packs and the associated paperwork at home was an issue for some coaches in relation to space. Space at leisure centres was limited and it was not possible to store the packs at the venues for them to collect before a visit. Distributing additional packs and paperwork to lifestyle coaches became a challenge as the trial progressed requiring resources to be sent via post or arranging packs to be collected in alternative locations.

Lifestyle coaches' suggestions for improving ActWELL intervention delivery

During support sessions, regular catch ups and final exit interviews lifestyle coaches highlighted some key points for consideration:

Trial information

Ensure research nurses provide sufficient information to trial participants when recruited to the study. Some lifestyle coaches mentioned participants were not made aware their role was voluntary. Often once this was explained their expectations of the coach changed and participants became more flexible. Some participants were not clear that the face to face sessions would take place in pre-agreed leisure centres, which had implications for their travel requirements. Others expected to be in a gym with a fitness coach to get personal training.

Lifestyle Coach Time commitment and paperwork

A realistic time commitment and a less paper heavy intervention is key for any future roll out. Some felt the role involved more paperwork and associated preparation time than initially suggested. Some lifestyle coaches found the paperwork onerous and would have preferred packs to be in a more logical order. Some found it difficult to navigate through the coach pack, however others had no issues with it.

There were suggestions that taking on participants would have been more manageable if allocations had been more evenly spread out at one per month, however others said they would have preferred to take on 3-4 at once. It seems this is down to individual preference and highlights the need for ensuring flexibility when working with volunteers.

Others commented the role was a bigger commitment than they had expected and thus felt they were letting the trial team down by not taking on and supporting their intended number of participants. Some also mentioned they had lost the enjoyment of their role, describing it as "beginning to feel like a 'job' at times".

Lifestyle Intervention visits and phone calls

There were suggestions to allocate more time for the face to face visits, and it was commonly felt that 60 minutes for visit 1 and 45 minutes for visit 2 was not enough time to build relationships with participants and they also liked to chat and ask questions. Some also felt there was too much information in visit 1 and that often participants had 'switched off' by the end.

More local options and consistently available meeting spaces would have been preferred. There were some suggestions that meetings could take place in other venues such as GP surgeries, community schools or community centres.

Improved mobile phones or an alternative method for contacting participants was a major theme. Some were happy to use their own phones but this led to additional data protection considerations for Breast Cancer Now.

Additional face to face visits were frequently suggested, either at six months or at the end of the project. Some commented final contact with participants was an anti climax. Lifestyle coaches would have appreciated the opportunity to meet up with participants at the end and find out the progress of individual participants they had supported.

Volunteer Support

As a volunteer, the lifestyle coach role had its challenges, particularly when faced with mental health issues of participants. Some also found the social element of their interaction had a big part to play and it was often hard to disentangle this from the protocol and stick to the role brief.

Several volunteers emphasised the importance of regular support and supervision needs to be built into the role to deal with issues arising. This included discussions on case load, providing feedback on whether they were meeting the expectations of the role and appraising competency of coaches. There were also suggestions for:

- Additional training and support around referrals if participants were struggling with mental health issues.
- Mentoring system and peer to peer support for volunteers.
- Developing clear guidelines and a key point of contact for coaches to ensure they have clarity on protocols for dealing with specific situations such as losing contact with a participant or dealing with a health condition and ill health.

The Volunteer Lifestyle Coach experience

Volunteering brings people together, builds confidence and develops new skills, improves mental health, and has a positive impact on health and wellbeing. It was important to Breast Cancer Now that volunteering as an ActWELL lifestyle coach was a positive and enjoyable experience, that volunteers felt supported and had the skills to deliver their role confidently.

It was also hoped that through their involvement in ActWELL and delivering a lifestyle intervention that lifestyle coaches would have an increased understanding of the link between lifestyle and breast cancer risk and make positive lifestyle behaviour changes around physical activity, weight management and alcohol.

Throughout the trial period lifestyle coaches were provided opportunities to share their motivations for applying for the role, their experiences of being

a volunteer with Breast Cancer Now and their involvement in the ActWELL trial. This included;

- Breast Cancer Now's volunteer lifestyle coach application form
- The trial team's ActWELL training day evaluation forms
- Informal feedback and discussions during group support sessions and ongoing email and telephone support
- Volunteer exit interviews,
- Breast Cancer Now's volunteer feedback form (Survey Monkey)
- The trial team's survey 'Being a lifestyle coach and you' (Survey Monkey)

The section below summarises this feedback, illustrating the lifestyle coaches' experiences of being involved in ActWELL and the impact it has had on them.

Experiences and motivations of an ActWELL lifestyle coach

The team of lifestyle coaches came from a variety of professional backgrounds including: health and social care, education, counselling, sport and fitness. This provided a diverse mix of skills and experiences to the project, which the word cloud image 'Employment, skills and experiences for lifestyle coaches' summarises.

There was a varied spread across the group of those in full time employment, retirement, studying or returning to formal education and those who were stay at home parents. This also related to their individual motivations for volunteering on the ActWELL project.

To understand motivations applicants were asked 'why they wanted to become a volunteer on the project' as part of their application. Describing their own personal interest in health and wellbeing, health promotion, supporting other women to improve their lifestyle and raising awareness of the link between lifestyle and cancer prevention were commonly cited. Some had a connection to breast cancer and wanted to support Breast Cancer Now and research into cancer prevention. Others wanted to give back to the community by sharing their skills, gain experience and the opportunity to try something different.

What volunteering on ActWELL has meant to the lifestyle coaches

Lifestyle coaches were sent a short Survey Monkey questionnaire 'Breast Cancer Now volunteer feedback form: ActWELL' when their role as an ActWELL lifestyle coach came to an end. In total this was sent to 41 volunteers with 27 completing it. In addition to this during the ActWELL celebration event in March 2019 the 29 volunteers who attended were asked to tell us about their experience on the project and what being involved has meant to them.

Overwhelmingly volunteers told us they had a positive experience volunteering on the project. Figure 7 shows that 100% of volunteers who completed the ActWELL volunteer feedback form enjoyed being a volunteer and it gave them a personal sense of achievement; common themes included:

- meeting new people
- the training and learning new skills
- supporting women to make positive changes to their lifestyle
- motivating others to take ownership of their health
- supporting the participants on a journey
- seeing the improvements women were making

Volunteers believed they were making a difference and contributing to improving women's lifestyle behaviours. It was frequently mentioned that it was a privilege to work alongside the women they supported and help them achieve their goals.

"I really enjoyed meeting new people and seeing their sense of achievement"

"I feel that I have made a big difference to the lives of the participants I have met over the course of the trial"

100% of respondents also said they were either very satisfied or satisfied with the role they had delivered and 100% would recommend volunteering with Breast Cancer Now to others. 93% reported they got satisfaction from seeing the results with some commenting that they enjoyed being involved in research and that contributing to research on cancer prevention was important to them. "Being involved in the research and being part of the bigger picture"; "I really enjoyed the experience and looking forward to hearing the results".

In terms of their own personal gains 85% responded to say they had met new people and made friends. Some lifestyle coaches described feeling more confident as a result of being involved in ActWELL. 85% said it gave them the chance to learn new skills or build on existing skills. For some it was an opportunity to try something new and several used the experience to change careers and have gone on to study counselling related courses in further education.

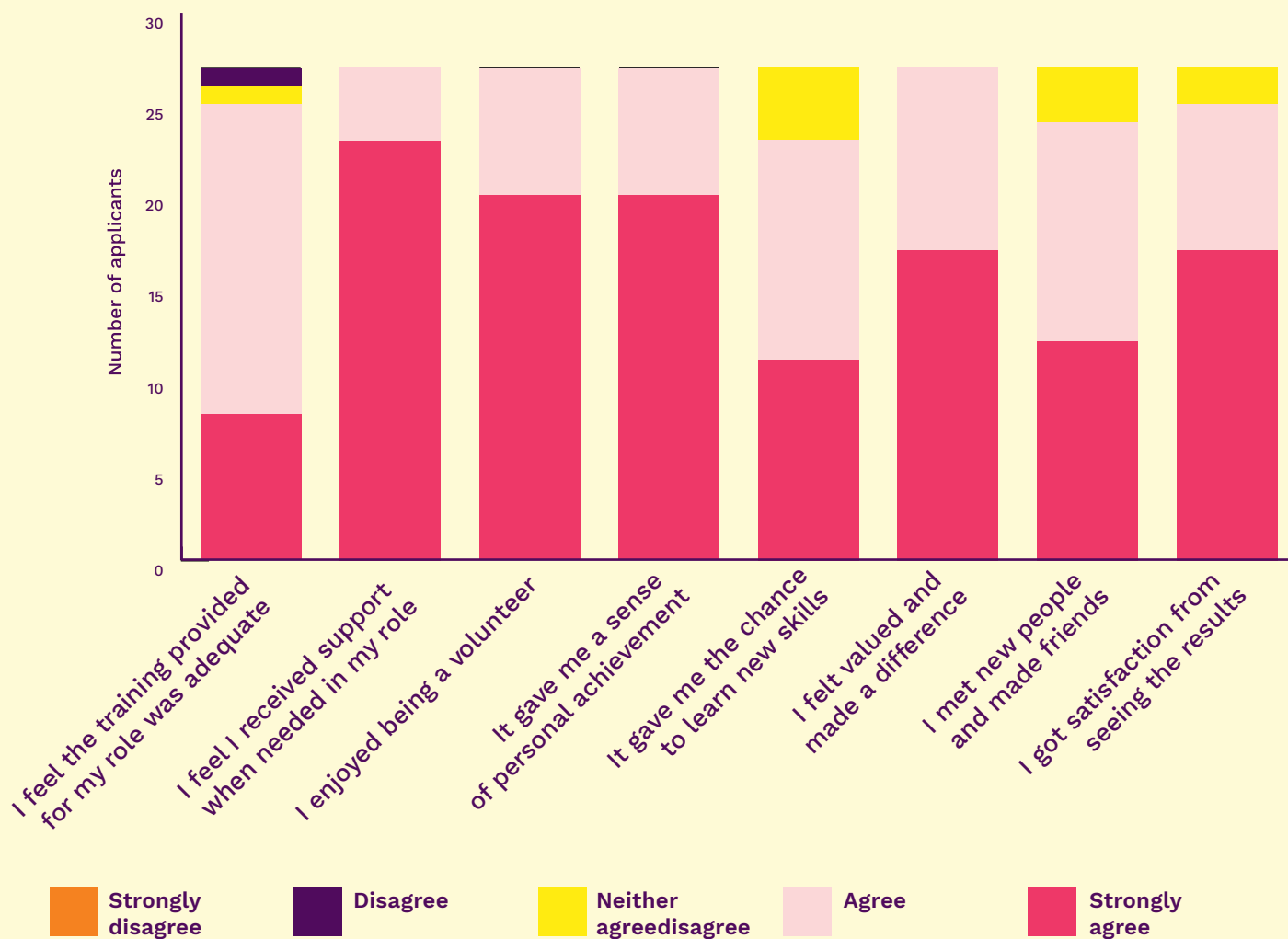
UNIVERSITY-STUDENT PUBLIC-HEALTH
 PHYSICAL-ACTIVITY EXERCISE-COACHING
 PROJECT-MANAGER CARER
 TEACHER VOLUNTEER COUNSELLING
 MOVE-MORE CHARITY-WORK MENTOR GP
SUPPORT-WORKER
 MEDICAL CBT RETIRED EDUCATION
 NUTRITION WALK-LEADER **NURSE** COUNSELLOR
 FITNESS-INSTRUCTOR
 BEHAVIOUR-CHANGE **HEALTH PSYCHOLOGIST**
 HEALTH PROMOTION

Image: Employment, skills and experience of lifestyle coaches

SKILL-DEVELOPMENT CANCER-PREVENTION
 EMPOWERING RETIRED VALUABLE WORK
 LISTENING BREAST-CANCER PHYSICAL SUPPORTING
 CHARITY **INSPIRING GIVE-BACK**
 RAISE-AWARENESS ACTIVE **HELPING**
FAMILY CONNECTION
 HEALTHY-LIFESTYLE INTEREST **HEALTH** FUN
 NEW-SKILLS **MEETING-PEOPLE** DIET
 PRIVILEGE
ENJOYMENT PREVENTION ACTIVITY
 HEALTH-PROMOTION VOLUNTEER
 IMPROVING-CONFIDENCE FITNESS **RETAINING-SKILLS**

Image: Motivations for becoming an ActWELL lifestyle coach

Figure 7: Volunteer experiences of being a Lifestyle Coach with Breast Cancer Now: How much do you agree or disagree with each of these statements



"It's been brilliant being part of the team and you actually feel quite privileged to be part of the journey these women are on"

Lifestyle coaches feel confident and have the skills to deliver the ActWELL intervention to participants

From the volunteer feedback form, most (95%) felt the training provided for the role was adequate. Feedback on the training was positive overall, however varied depending on which training session they attended. Those who attended the first training session fed back they were given too much information and felt overwhelmed by the end of the two days.

"We had a lot of information at the start of the project. Any way to simplify this would be helpful initially"

They suggested having more focus on delivering the intervention, more opportunities to role play to practice delivery and go through the paperwork in more detail. The ActWELL coach and participant packs had not been finalised and they found the layout quite confusing when they tried to use them in the training session and practice afterwards.

"A lot to take in in a short time. Would be better and less confusing if packs were finalised and sorted correctly"

This feedback was taken on board and revised for future training. Those who attended the first training were invited back for a one-day refresher training incorporated into the September 2017 training. Six lifestyle coaches took up this opportunity, they all found it helpful and a good opportunity to catch up with other coaches again.

"I found the refresher day super helpful. It's really brought it all together for me and I feel much more prepared and confident about what I'm doing"

"Found coming back for 'refresher' session very useful as gave opportunity to ask specific questions raised by practice sessions and reinforced protocols"

As previously mentioned day two of the training in February 2018 was abandoned due to poor weather conditions. The training session was rescheduled a couple of weeks later. This group of volunteers fed back that this had been beneficial commenting that it gave them an opportunity to:

- reflect on the training and review the paperwork
- carry out practice sessions and raise questions or issues they had with the trial team
- recap the programme and share experiences from practice sessions with others
- meet up with other volunteers again

Lifestyle coaches found completing the two practice sessions with friends and family beneficial, however nothing gave them more confidence than delivering their first session and putting it all into practice.

Some developed their own checklists and prompts for delivering sessions which they shared with others. They also found it helpful to hear from active lifestyle coaches invited to training sessions to share their experience of delivering the intervention to participants.

Arranging inductions in each of the leisure centres and having the opportunity to meet staff and go through booking procedures was viewed as important and gave them confidence to have a contact at each leisure centre who could support them with any issues.

Lifestyle coaches feel supported and valued in their role.

Figure 7 shows that 100% of volunteers who completed the feedback form received support when needed in their role and that they felt valued and made a difference. Lifestyle coaches carried out their role remotely and had limited face to face contact with the ActWELL Project Officer and trial team after training. Despite this, they consistently fed back that they felt the support from both Breast Cancer Now and the University of Dundee was excellent and that both the ActWELL Project Officer and trial manager were approachable, easy to access (by phone / email) and were quick to respond to questions and dealt with any issues and concerns with participants efficiently. They found this helpful and reassuring.

"I got lots of support from [the ActWELL Project Officer] on the phone and by email"

"I felt totally supported throughout the trial, both the ActWELL Project Officer and trial manager were easy to access by phone or email and quick to respond which was helpful"

Organising regular group support sessions in each of the ActWELL delivery sites and inviting them to the ActWELL celebration event contributed to volunteers feeling valued and supported. They enjoyed having the opportunity to meet up regularly with other volunteers, share experiences and challenges and discuss solutions or different approaches to overcome issues. Some commented that the ActWELL Project Officer taking the time to meet with them locally demonstrated a commitment to ensuring volunteers felt appreciated, even if they were unable to attend. They also felt communication and updates on the project through regular emails and the ActWELL Newsletter were adequate and welcomed other little gestures including regular catch up calls and emails, volunteer anniversary and Christmas cards.

"It was nice to feel valued with the little touches e.g. the Christmas card and thank you card".

Lifestyle coaches were happy to be approached as case studies for media, videos and news articles and always obliged. They felt it was another way to support the project.

Awareness and behaviour change

The trial team were interested in establishing whether taking part in ActWELL had prompted any changes to the lifestyle coaches own health and wellbeing and how their experience might have influenced their own thoughts and actions. They created a short survey for lifestyle coaches to complete 'Being a lifestyle coach and you' which was sent to 45 lifestyle coaches.

In total 29 lifestyle coaches completed the survey which highlighted that being involved in the ActWELL project had positive impacts on their own awareness, knowledge and behaviours.

Lifestyle coaches reported having an increased understanding and awareness of the link between lifestyle behaviours and breast cancer.

Since becoming an ActWELL lifestyle coach:

- 82% of respondents felt they were more conscious of their own personal lifestyle habits
- 45% have started seeking more information about the links between lifestyle and breast cancer
- 48% have started seeking more information about how to change lifestyle

"I've been conscious of sedentary time and portion control"

"I watch more television programmes and read more articles that examine healthy lifestyle and current research on links to health than previously"

However, some felt that they were already aware of the link between lifestyle and breast cancer and had access to relevant information due to the nature of their roles as health professionals.

Lifestyle coaches have made positive changes to their personal lifestyle behaviours that are linked to risk of breast cancer (diet, weight, alcohol and physical activity)

Weight Management and alcohol

In relation to behaviour change, being involved in the ActWELL project has led to some coaches making changes to their own personal behaviour in relation to weight, 43% and alcohol 37%, see figure 8. Of those who completed the survey 25% reported that changes to drinking alcohol were not relevant to them because they either didn't drink or believed they drank very little alcohol anyway.

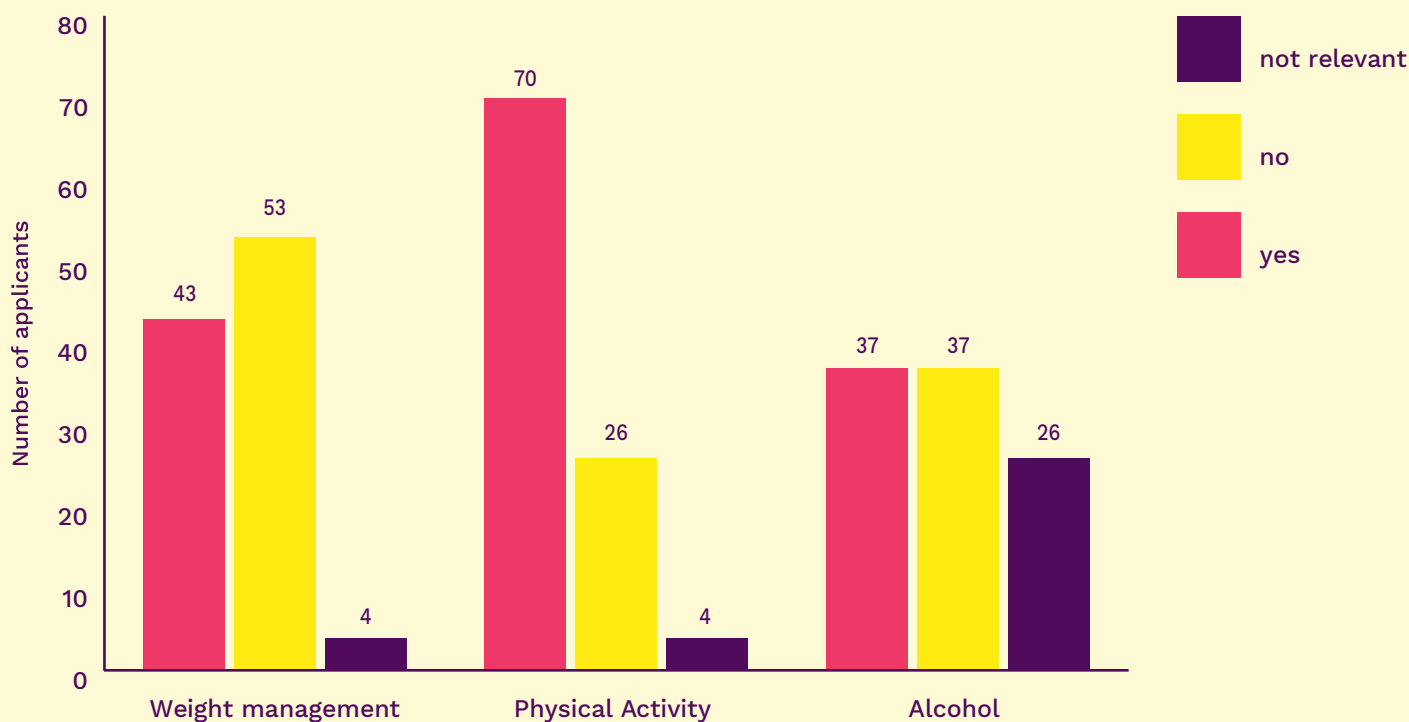
"I use the advice to calculate my calories when I want to lose a couple of pounds"

29% reported they had lost weight because of being involved in the project and 67% had stayed the same, only one person reported their weight had increased.

"I have set walking challenges and using the pedometer at all times. It is a great motivator"

"The exercise of 10 mins walking = 1.000 steps was impressive. I make more time to walk now and try to use the pedometer daily for feedback and encouragement"

Figure 8: Did the ActWELL training and coaching influence you to make changes relating to your own personal lifestyle habits?



Physical Activity

However, being involved in ActWELL appears to have had the biggest impact on physical activity levels with 70% reporting they had increased this as a result of being involved in ActWELL (figure 8).

Modelling good behaviour

One common theme from lifestyle coaches was they made changes to their own lifestyle habits because they didn't feel they could give advice to participants that they could not follow themselves. This helped them make their own changes or maintain a healthy lifestyle.

"If I felt I couldn't be bothered doing a workout or going out for a walk in the drizzle I thought of the women I was coaching and what I would say to them"

"Once I was working with the participants I felt I needed to make some changes myself, otherwise I would have felt slightly hypocritical. Walking my talk is important to me"

Some lifestyle coaches felt they should be setting a good example to participants and didn't want to be perceived as overweight. They often made comments to the ActWELL Project Officer that some of their participants appeared slimmer than them and they felt they should be taking the project's advice to help them lose weight.

Unintended Outcomes

Involvement in ActWELL has had a positive impact on some lifestyle coaches' professional roles. They found the training, resources and techniques could be applied in their workplace and have used it to inform and support colleagues. Others have given advice to colleagues in the workplace on healthy eating and encouraged staff to get out and be active at lunchtime. One individual mentioned she has been using her knowledge to help her workplace to achieve the Healthy Working Lives award.

Four lifestyle coaches have gone on to study courses related to counselling, coaching and Cognitive Behavioural Therapy (CBT) since becoming an ActWELL Lifestyle Coach. For some it has been to follow a personal interest in coaching and counselling, others have used their experience as a stepping stone to changing career. Six volunteers have gone on to continue using their skills as a lifestyle coach on the BeWEL project with Bowel Cancer UK.

As a result of their involvement in the project many reported they have gone on to have conversations with friends and family about their personal lifestyle habits and supported them to make changes. When explaining their involvement in the study to others they felt they could use it as an opening for conversations about lifestyle. From the survey results 'Being a lifestyle coach and you':

71% of volunteers
discussed weight management

79% of volunteers
discussed physical activity

52% of volunteers
discussed alcohol

"I have told family members about the link between weight gain and breast cancer"

"I have used the information with my husband who is keen to lose weight. He finds the dietary advice clear and easy to follow"

Some found discussing weight a sensitive issue with friends and family and often only talked about alcohol in relation to calorie control. Comments suggest it was easier to talk about physical activity, portion control, and tips for changes to diet and their own experiences of being a lifestyle coach. Encouraging others to join them on walks, runs or taking part in exercise classes and adopting changes to diets with their partners have supported behaviour change.

"My friends and I have started running together and are now up to a 5K"

"Suggested meeting friends for walks or activities rather than a pub or cafe"

"I feel more comfortable encouraging others if I am also doing it"

CONCLUSION

Breast Cancer Now's involvement in ActWELL demonstrates it is possible to recruit, train and deploy volunteer lifestyle coaches to deliver a weight management intervention in a community setting.

In total Breast Cancer Now received 170 applications to become a lifestyle coach. This demonstrates the willingness of individuals to donate their time as a volunteer to deliver a behaviour change lifestyle intervention. The role mainly appealed to women, and particularly those over 35, which is perhaps reflective of their desire to offer support to people they can relate to. It also highlights the desire people have in sharing their skills and experiences to support research into cancer prevention and raise awareness of lifestyle behaviours in relation to breast cancer risk.

Delivering the ActWELL lifestyle intervention resulted in some unintended, yet significant, outcomes for the lifestyle coaches themselves. Their involvement led to their increased awareness of the link between lifestyle behaviours and breast cancer risk, and positive changes to their own behaviours and weight. They also developed new skills and had the opportunity to try something new, in some cases leading to a change in career.

It is important to credit the goodwill of both the volunteer lifestyle coaches and the leisure centres in ensuring the successful delivery of ActWELL. Throughout the trial lifestyle coaches demonstrated enthusiasm, perseverance and resilience with a commitment to delivering the intervention to the best of their abilities. The intervention could not have been delivered without the generosity of the four leisure trusts who allowed the use of their venues as meeting spaces to accommodate the face to face meetings. Leisure centre staff were always friendly, welcoming and willing to be flexible.

However, to ensure a complex project like ActWELL is successfully delivered requires significant staffing resource with a dedicated member of staff to recruit and provide ongoing support to the volunteers, co-ordinating project delivery and acting as a mediator between the various partners involved. If the project was to be rolled out consideration would need to be given as to the appropriateness and practicalities of the venues chosen for meetings to take place. It is also important to allow sufficient time for project planning and set up to take place. Ultimately this would ensure volunteer recruitment processes and associated data collection issues are agreed, appropriate data handling procedures have been considered and implemented and any partnership agreements are in place before the project begins.



Recommendations and learnings

Outlined below are several considerations and recommendations based on the learning from Breast Cancer Now delivering the ActWELL project that would need to be considered to make any future programme roll out viable.

Table 12: Summary of recommendations

<p>Project planning</p>	<p>Allow a minimum of six months' lead in time for the project co-ordinator to plan the project, set out timelines and establish and agree all processes before volunteer recruitment begins.</p> <p>Ensure there is a process for collecting and storing both volunteers' and participants' personal data</p> <p>Where sharing personal details to volunteers is a requirement ensure a secure platform is chosen, e.g. Office 365 SharePoint, and provide volunteers with an organisational email address.</p> <p>Set out clear guidance and procedures for volunteers on confidentiality and data handling including putting in place a volunteer data breach process.</p> <p>Provide appropriate resources (i.e. mobile phone) and guidance to allow volunteers to contact participants in a safe and secure way</p>
<p>Project Staffing</p>	<p>Having a dedicated staff resource to co-ordinate the delivery of the project and support volunteers is essential. Provide sufficient project staffing for project management, co-ordination and delivery, establishing relationships and administrative tasks:</p> <ul style="list-style-type: none"> · Project manager: developing processes and procedures (data handling/ GDPR), developing relationships with partners, risk management, managing project officers · Project officer(s): implementation in geographical areas, volunteer recruitment, volunteer training, overall volunteer management and supporting, resolving issues · Project administrator: support around volunteer recruitment and potentially contacting participants, administrative support for events and training <p>It is also important to consider where staff are based in relation to volunteers delivering the project and whether remote management is necessary.</p>
<p>Developing the volunteering role</p>	<p>Consider expectations being placed on volunteers:</p> <ul style="list-style-type: none"> • Capacity to deliver • Location of venues and travel • Suitability for role: experience, skills and qualifications necessary <p>Identify realistic number of volunteers required.</p> <p>Ensure the role can be delivered flexibly by volunteers at a time and place that is convenient.</p>
<p>Volunteer management</p>	<p>Ensure appropriate organisational volunteer policies and procedures are in place.</p> <p>Allow adequate time for volunteer recruitment and selection. Important to consider geographical spread of project and where volunteer recruitment is required.</p> <p>Where necessary phase volunteer recruitment across multiple project sites to allow sufficient time to promote opportunities and carry out selection.</p> <p>Provide appropriate support for volunteers - particularly where the role is delivered remotely.</p> <p>Consider budget for volunteer expenses and travel requirements of volunteers.</p> <p>Provide opportunities for volunteers to come together more often for support and to share experiences.</p>

Participant / Service user recruitment	<p>Consider how participant recruitment would take place and who would be responsible for:</p> <ul style="list-style-type: none"> • Determining where recruitment would take place • Participants receiving information about the project • Screening participants for suitability / eligibility • Collecting personal details <p>Consider any data sharing of personal data between organisations.</p>
Project management	<p>Establish a core project team for delivery and a steering group to report into regularly.</p> <p>Create a risk register and ensure this is updated regularly and identified risks are managed.</p> <p>Maintain regular contact with key stakeholders providing updates on project progress and success.</p>
Project delivery	<p>Identify suitable venues: appropriate meeting spaces, geography and accessibility of venues needs to be considered.</p> <p>Identify venues that will allow resources and materials to be stored.</p> <p>Have signed partnership agreements in place with partner organisations hosting any meeting spaces.</p>
Monitoring and evaluation	<p>Develop an evaluation plan at the outset and consider what success looks like and how to measure these.</p> <p>Put in place appropriate tools for collecting data from participants and volunteers.</p> <p>Log ongoing issues and challenges in a change log.</p> <p>Consider how results will be disseminated to key project stakeholders.</p>

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APPENDIX 1: ACTWELL VOLUNTEER DATA FLOW

Volunteer Recruitment

Method: Applicants complete on-line application form via website.

Volunteerscot@ email account receives notifications with full details each time someone applies.

These emails are categorised & saved in restricted personnel folders, emails in inbox deleted.

Data collected; contact details, consented sensitive personal data (option to provide), equalities data, referee contact details & consent for marketing.



Processing Volunteer

Full webform downloaded from CMS at end of recruitment cycle - password protected & saved in Restricted Personnel folder (Information remains on CMS until the web team delete it as per there data retention schedule)

Separate spreadsheets created from this to:

1. Monitoring & Evaluation purposes.
2. Manage recruitment process



2. Manage Recruitment Process Spreadsheets

Method: Application Tracker Spreadsheet – Password Protected & saved in ActWELL Restricted Personnel Folder.

Data: Name, Contact details, referee details only, application outcome, invite to selection/ training.

Method: Application information spreadsheet for Trial Team selection purposes. Password protected.

Data: Applicant Name, application details (skills/ why you would like to volunteer) only.



1. Monitoring & Evaluation

Anonymised Equalities monitoring data spreadsheet for all applicants saved in personnel folder.

Webform downloaded for all applicants. To be categorised by volunteer applicant status (Referee contact details and equalities monitoring data are deleted from webform download)

Issues log to document all significant issues raised by volunteers from any interactions such as email, support sessions, individual 1 2 1 catch up's etc.



Managing Recruitment: Process Successful volunteers contacted for phone interview/ selection session.

Unsuccessful volunteers emailed.

Tracker spreadsheet updated.

Data: contact details removed from recruitment tracker spreadsheet for monitoring purposes & to aid Data Team with R.E import saved in ActWELL Personnel folder.



Method: Successful applicants invited to training by email. Successful applicants referees followed up via email.

Data: personal feedback on applicant stored in electronic personnel folders.

Method: Applicant spreadsheet sent to Trial team for them to send out training materials, book accomodation & follow up with ACTWELL resources. Spreadsheet is password protected & sent securely.

Data: name, email, telephone & address.



Data: Active volunteers provide emergency contact details, sign a volunteer agreement, complete an availability form & confirm personal contact details via email/or post.

Method: Returned paper documents are stored in a locked filing cabinet & destroyed once scanned & saved in personnel folders. Returned electronic documents are stored in the restricted access personnel folder.

Exploring with POD the use fo Cascade to store personal details & application infomration for all all active volunteers.



Processing/storing volunteer data: Data Team import applicants to R.E. (includes successful & unsuccessful applicants who opted into marketing).

Method: Data team download CMS webform & ActWELL project officer shares Application Tracker (via J drive), spreadsheet for application outcome, Volunteer "Status".

Data: stored on R.E.: Name, contact details, volunteer status, date applied, invite to training, availability, consent for marketing.



In the event of a volunteer handing over a participant to another volunteer, verbal consent is obtained to put them in touch with each other for any questions/ queries.

APPENDIX 2: ACTWELL PARTICIPANT DATA FLOW

Screening centre

Data: Interested participant's contact details
Method(s): Paper

Data: Participant contact details, ID, & some baseline health measurements number

Method(s): Spread sheet via Sharepoint / encrypted email (historically)

Breast Cancer Now

Data: Details of ineligible participants/
Queries relating to participants

Method(s): email/ phone

Volunteers

Volunteers contact participants by text/ phone, and keep paper records on participants (locked storage)

***Baseline health measurements sent to volunteers:**

Weight & height
BMI
Physical activity
Target weight
Calorie prescription

Research Nurses

Telephone screening of participants conducted in line with NHS data protection procedures. Baseline measurement* carried out with participants.

Data: Baseline measurements & contact details
Method(s): Shared Database, Open Clinica

Data: Participant contact details, ID number, & some baseline measurements
Method(s): Spread sheet via secure file share website (UoD Box)

Trial team

Data: Final, anonymised participant data and Coach record Form
Method(s): Paper via post

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Breast Cancer Now is a working name of Breast Cancer Care and Breast Cancer Now, a charity registered in England and Wales (1160558) and Scotland (SC045584), and a business name of the registered charity in the Isle of Man (1200).