

# **Darkside Rising CIC Strength in Cancer Project Evaluation Report**

**December 2021**

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In collaboration with Darkside Rising CIC.

The Darkside Rising CIC Strength in Cancer project was supported by an investment from Wave 10 of the Lincolnshire Mental Health Promotion Fund.



The evaluation was funded by the Productivity Programme.



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HADS Hospital Anxiety and Depression Scale

## 1. Introduction

Darkside Rising CIC was established in January 2020 and is a non-profit organisation based in Lincoln. They are dedicated to challenging the perception of female strength, resilience and power through innovative physical training and mindful arts projects. Darkside Rising arose from 6 years of experience running Darkside Training, a women's strength and powerlifting gym. Darkside Training donates their gym space to Darkside Rising in order to improve accessibility and remove barriers to entry such as cost or health concerns.

Aimed at women only, the Darkside Rising CIC Strength in Cancer Project is a 26week strength training programme that is highly individualised, with sessions capped at 4 women to ensure they receive focused, personal coaching and exercise programming. The Strength in Cancer project was part of Wave 10 of the Managed Care Network funded by Lincolnshire County Council's Mental Health Promotion Fund and managed by Lincolnshire Partnership NHS Foundation Trust (LPFT).

The purpose of this report is to explore the Darkside Rising CIC Strength in Cancer project by examining data collected by Darkside CIC and the University of Lincoln in relation to the impact and receipt of the project. The specific aims were to:

1. Assess service uptake, accessibility, adherence and attrition over the 26-week programme, comparing online and in-person streams.
2. Assess perceptions of strength training as a woman, and as a woman with cancer, including how this changes over the course of the programme.
3. Assess how perceptions of being 'strong' influence the cancer recovery journey.

In order to assess these aims, routine data collected by Darkside Rising CIC was analysed alongside data captured through semi-structured, one-to-one participant interviews. Therefore, this report examines the following:

- Participant sociodemographic data
- Participant attendance
- Piper Fatigue scale (Piper et al. 1998) (measured at 0, 13 and 26weeks)
- Hospital Anxiety and Depression scale (HADS) (Zigmond and Snaith, 1983) (measured at 0, 13 and 26weeks)
- Thematic analysis of 21 semi-structured participant interviews (conducted at 0 and 26weeks)

It is important to note, where interviewees names are used these are pseudonyms to protect the participants' identity.

## 2. Programme Data

Participants accessing the Strength in Cancer project were required to complete a series of questionnaires compiled by Darkside Rising CIC. These questionnaires, alongside participants' personal information, comprised of a series of validated tools including Piper Fatigue scale (Piper et al. 1998) and HADS (Zigmond and Snaith, 1983). In addition to baseline data, all participants were required to complete the same paperwork at 13 and 26 weeks. All data collected was recorded by Darkside Rising CIC personnel to enable the monitoring and analysis of data.

Twenty-seven participants were recruited to the programme, with twenty-one officially starting and consenting for their data to be shared with the University of Lincoln for the evaluation. Of those twenty-one who consented, the average age was 54.43 years ( $\pm 12.71$ ) with an age range of eighteen to seventy-five years. For the group, 62% (13) were in employment, 24% (5) were retired, 4.5% (1) in full time education and 9.5% (2) currently unemployed.

In establishing how the participants had heard about the programme the following responses were given:

**Table 1: Source of programme promotion leading to programme uptake**

Source of Programme Promotion	No. of Responses
Lincoln Cancer Support Facebook page	13
Doctor's surgery Facebook page	4
Hospital Employee website	1
Referral from Sports Therapist	1
Member of Darkside Training	1
Referral from other participant	1

For those consenting, attending participants had been diagnosed with a variety of cancers, as indicated in table 2 below. Of the participants, 76% (16) were still undergoing active treatment, with the remaining 24% (5) between five- and twelve-months post treatment.

**Table 2: Participant numbers in relation to type of cancer**

Type of Cancer	No. Of Participants
Brain tumour	1
Breast	11
Lung	1
Melanoma/ Skin	2
Non-Hodgkins Lymphoma	1
Oesophageal	1
Ovarian	3
Thyroid	1

Darkside Rising CIC offered participants the choice of either online or face-to-face sessions for the programme. Of the twenty-one, 62% (13) opted to attend sessions at the Darkside Training gym, with the remaining 38% (8) choosing the live online Zoom classes. Across the two delivery formats, over the 26week programme, average attendance was 48% ( $\pm 28.81$ ), with individual attendance ranging from 92% (24 out of 26weeks) to 3% (1 out of 26weeks). Whilst these figures may seem relatively low, it is important to note that 7 (33%) of the group dropped out during the course of the programme due to health issues. Therefore, for those that attended all 26weeks, average attendance was 62% ( $\pm 19.73$ ). It is also important to acknowledge that 76% of the group were undergoing active treatment at the time of the programme and Covid-19 was still extremely prevalent.

Of those who completed the programme 11 (52%) participants completed both the Piper Fatigue scale (Piper et al. 1998) and the HADS (Zigmond and Snaith, 1983) at week 1, 13 and 26. Due to limited numbers statistical analysis would hold little meaning, therefore a descriptive analysis of the data is provided.

In reporting fatigue, at week 1 the majority of participants (8 out of 11) identified as experiencing moderate to severe levels of fatigue (4-6 moderate, 7+ severe), with a group average of 5.18 ( $\pm 2.03$ ). Only 3 of the 11 participants scored fatigue as mild (1-3). By week 13, the group average had reduced to 3.4 ( $\pm 1.98$ ), with 6 of the 11 participants now reporting fatigue as mild (1-3), a clear improvement from the baseline data. There was another small reduction at the 26week point, with a group average of 3.34 ( $\pm 1.79$ ) and an increase to 7 participants reporting mild levels of fatigue. It is

important to note that 8 of the 11 participants all saw a continued reduction in fatigue across the 26 weeks.

The HADS provided a score for both anxiety and depression. In examining the scores for anxiety, for the 11 participants with complete data, the group average was 9.36 ( $\pm 3.38$ ), which would be considered 'borderline' (8-10). 4 of these individuals scored over 11, which using the HADS categories, would be considered 'abnormal' (11-21), in the sense of presenting with anxiety. Only 2 of the 11 fell into the 'normal' (0-7) category. By week 13, there was a group decrease to 6.81 ( $\pm 3.76$ ), which on average meant the group were categorised as 'normal'. Only 2 individuals' scores were in the 'abnormal' category (11-21), a reduction of 2 from the initial data. At week 26, there was a further reduction of the group average to 5.54 ( $\pm 3.17$ ), with no one in the 'abnormal' category and only 3 in the 'borderline' category. Interestingly, similar patterns were not observed for depression. At baseline, the group average was 6.36 ( $\pm 3.64$ ), using the same category as previously detailed, this scored the group as 'normal' (0-7). 2 of the 11 individually scored between 11 and 21, therefore identified as 'abnormal'. At week 13 there was a considerable decrease of the group average to 3.36 ( $\pm 1.96$ ), with all group members individually scoring between 0 and 7, classified as 'normal'. By week 26, there was a small increase of the group average by 0.36, to 3.72 ( $\pm 2.00$ ), with 9 of the participants' scores either remaining the same or going up. Evidently, the group average remained in the 'normal' classification for the duration of the programme.

### 3 Programme Design and Delivery

Data suggested that the participant experience had been influenced by both the way the programme had been specifically designed and how it was delivered. Overarching themes explored the personalised designed of the programme, delivery mechanisms of online versus face-to-face and the role of the instructor.

#### 3.1 Expectations and preconceived Ideas of the programme

Going into the programme, it was interesting to explore what participants' expectations were for the programme or any preconceived ideas they might have held. Whilst most of the participants had some understanding of what 'strength training' might involve, others were less clear on what type of exercises they would be participating in.

*I thought it would be, you know, perhaps music and star jumps and lunges, you know... I never thought I'd be lifting weights, I mean we joke about it, but I never thought I would be lifting weights (Judy, interview 2).*

Many participants felt unsure what the programme would entail or what they would be doing each week. Responses included 'I had no idea' or 'I hadn't a clue':

*I absolutely had no idea whatsoever. I really, I couldn't really envisage it at all, to be to be quite honest. I've done I've done Pilates as well and I kind of wondered if it was along those sorts of lines, you know, for sort of core strengthening, as well. So, yeah, I really didn't, I really didn't know, I had no, no idea what (Alison, interview 1).*

*I have no idea, I wondered whether it would be cardiovascular. I did think it was going to be something about stretching, I hoped it would be stretching and things. And I did hope that there might be a bit of like, yoga - ery bits at the end. And that I didn't really know, I sort of thought it would be, I thought I'd go along, give it a go (June, Interview 2).*

The concept of lifting weights seemed surprising to some, and it was unclear whether participants attributed this to being a woman, or as someone with cancer. In contrast, for those who did understand what strength training would involve, still seemed unclear as to how it would work, particularly given the age of some of the participants and yet, as Claire came to recognise, the programme was tailored to suit everyone attending.

*And like, to be honest, 'cause I knew it was a weightlifting gym, I thought it was basically we're gonna go in and we're gonna do weight lifting and that didn't, we didn't do that for quite a while which is, obviously pretty makes a lot of sense, 'cause I mean the two la... the two ladies that go when I go there and you know they're both grandparents uhm and they've never done anything like that before. I'm not, so I was a bit like hmm... how do they, because, but actually turns out uhm, through like the surgery and everything else that is exactly what I needed 'cause I wouldn't be able to do it anyway, so needed to sort of take it quite slow and they were, they were just as hard really anyway, so uhm yeah (Claire, interview 2).*

Attending the programme online also brought its own uncertainty, this primarily related to wondering how it would work. By not attending 'in person' and not having access to specialist equipment, for some, comprehending how this would work in practice was unclear.

*You know, big heavyweights in a, you know, in a big you know cold clattery old gym so I had, I didn't really, I didn't really know what to expect and obviously because we don't have all of that equipment at home (Alison, interview 2).*

The participant's initial lack of awareness of what the programme would involve is an interesting finding, given that participants had signed up to the programme voluntarily. Regardless of those initial thoughts, participants who completed the programme reported that their original goals or expectations had been met or exceeded.

*I've got much more than I expected. I mean, I was very hesitant at joining, and I thought, 'oh, will I stick to it? Will I stick to it? And I'm not sure I'm gonna like it. I'm gonna feel really nervous. So my expectations were 'oh I might last a little bit'. But my expectations have been blown away because it's just been, it's one of the best things I've ever done in my life (Elaine, interview 2).*

### 3.2 Programme design

As previously identified in 3.1, participants were surprised by the design of the programme and had never expected to be weightlifting. Beyond exceeding their expectations, participants believed that sessions were not like any standard exercise class they had previously attended.

*It's just when you say an exercise class you think urgh, but I don't feel like its an exercise, I don't know how to put it, it doesn't feel like an exercise class. It's just fun! (Judy, interview, 2).*

The perceived monotony of a *typical* exercise class had been dismissed and participants enjoyed attending the programme as it was viewed to be something different to the norm. Apart from the activity itself of weightlifting, these ideas appeared to arise from participants appreciating how the design of the programme had been individually tailored to suit each of them, according to their capabilities.

*The exercises that Rachel had been putting, that's put in place she's very much individualised it when we've come, even though there's three or four of us that are doing at the same time, she's got different exercises for each of us, and that she takes into account our capabilities, and you know, in any difficulties that we might be either experiencing on that particular day, or that she's aware of beforehand (Alison, interview 2).*

Participants recognised not only how the programme was personalised prior to sessions but how it was also adapted on the day depending on what participants felt able to do, whilst still providing the

same training effects.

*So she came up with something totally different with the same effect that I could do no trouble at all (Judy, interview 2).*

Evidently, this was an ongoing process and participants could see how the programme design continued to evolve across the duration of the programme to meet their individual needs.

*She (Rachel) has a plan of what we're going to do each session and that is tailored, you know she's making notes every week. So if there's something you can't do, or you struggled last week, she's adapted it... we could all be doing the same exercise, but tailored to suit all three of us (Judy, interview 2).*

This individualised approach was acknowledged by a number of participants and in some instances, the programme appeared so personalised that some participants felt they had been given a personal trainer, despite attending as part of a group. Whilst some seemed almost surprised about this, ultimately, they believed it had really helped.

*I think that was quite interesting to be able to have that, so like a more of a personal trainer, even though we're in a group setting and so that's something that was the thing that I thought might be really handy and useful, and it has been, of course (Ellie, interview 2).*

Finally and perhaps most importantly, participants expressed a feeling of complete safety when embarking on and attending the programme, placing their trust in both the programme and instructor.

*I feel perfectly safe in her hands... you feel totally safe going (Judy, interview 2).*

### 3.3 Online versus face-to-face

One particular novel aspect of the programme, and in response to the Covid-19 pandemic, was to offer participants the option of attending in person or virtually via the Zoom online platform. When questioned about these options, participant choice was primarily dictated by travel time to the Darkside Training gym and work-related commitments.

*I think, yeah, convenience, because if you've got to travel somewhere, I wouldn't travel into Lincoln anyway, but even if it was local, you have to go outside, get in the car, travel, it adds on at least extra half hour, doesn't it, at least yeah and it's more of an effort, I think (Nicole, interview 2).*

The convenience of being able to attend the session from the comfort of their home and not requiring the additional effort of travel was viewed as a positive however it was noted that in some instances work commitments meant that online was the only option available. Some participants had been afforded the time off from work to attend but when combined with travel time, this had meant an extended release from work, which was not possible.

*... obviously I was doing it online and not going into the gym sadly. I mean it would have been nice to have been able to go into the gym with Rachel, but it was just that it was the travel that was prohibitive (Alison, interview 2).*

Despite the obvious difference in delivery methods, those who had opted for online delivery did not see this as a barrier. It was acknowledged, that there was some awkwardness when communicating through a screen, but it was felt that due to the pandemic, many had now adapted to this way of working, which has become a more widespread practice. One challenge that was recognised however, was the visibility achievable through the screen, for example the participant fitting their whole body in shot so that Rachel could see the full exercise being performed.

*I think the only challenge is trying to make sure that the video could see you properly like one minute you'd be standing up exercise and then sitting down (Nicole, interview 2).*

This experience was not reported by everyone, and others were surprised at how effective online delivery could be, in the sense that they could be in their own home, with limited equipment, performing adapted exercises and still be able to gain the physical and psychological benefits of training in this way.

*... it's been really like pleasantly surprising and I've been really, you know, really delighted by what has been delivered... I'm doing it in my own home and it's just nice and obviously Rachel's doing it in sort of in the gym arena and her home setup. Uhm, but I've been able to succeed and we were sent some resistance bands... but the exercises that we've been doing, we've been able to do at home quite easily and successfully using a chair or you know, and on the floor and using a cushion and things like that. It's been, you know, it's been easy to adapt... I've been able to do the exercises, feel the benefit, know that I've been exercising, feel the benefits of the exercises, without a whole raft of gym equipment (Alison interview 2).*

### 3.4 Role of the instructor

Across all participant interviews, the role of the instructor featured strongly, ranging from Rachel's skillset to how she related to the groups. Participant comments suggested that it was Rachel who had really influenced the participant experience and had been instrumental in their attendance of the programme.

Participants recognised the specialist training that Rachel had undergone, with reference made to being '*trained specifically for cancer people*'. Acknowledgement of such specialist training appeared to increase participant confidence in both the programme and Rachel. Comments went beyond specialist instructor training and highlighted Rachel's broader skillset and approach to the sessions. Her ability to personalise the exercise programme and adapt exercises in real time, whilst still supporting others was commended.

*She really thinks on her feet, she's very good at that... it's really done for individual*

*people... She really works with each one of us. I don't know how she does it. She's brilliant really (Anna, interview 2).*

Rachel's ability to relate to the participants was also a prominent theme and the relationship that she had built with them, regardless of whether face-to-face or online. Her warm disposition was welcomed and as one participant commented, '*she's become a bit more of a friend... she's a really lovely woman*' (*Judy, interview 2*). A number of participants made reference to how Rachel could relate to them and she had developed such a relationship with the participants that she appeared accepted as one of them, '*she can relate to all of us*' (*Judy, interview 2*). Furthermore, Rachel had also managed to tackle some of those misconceptions of stereotypical gym-based exercise, which can often be perceived as a barrier to exercise (also discussed in section 4.3).

*Although she's incredibly fit but that's her job, she's not... don't feel like I'm being taught by little skinny gym bunny. I don't mean that nastily. Do you know what I mean, she's a real person (Judy, interview 2).*

Some participants made reference to stereotypes relating to lycra, lifting big weights and gym bunnies and yet despite all of these being true to some extent, Rachel was not placed in any of these categories and instead viewed as a '*real person*'.

### 3.5 Space and atmosphere

Whilst the programme design and delivery appeared integral to the participant experience, the space where the exercise took place and the atmosphere created within the sessions also played a key role. When discussing the Darkside Training gym many participants were keen to articulate that it wasn't a 'normal' gym and that was a real positive for them. Many comments about the physical space highlighted that participants felt it had been created by women, for women and perhaps more importantly, this was a stark contrast to previous gym environments they had experienced. Joanne shared her initial perceptions of the Darkside Training gym.

*Well, they've got a lovely big chalkboard up with all kinds of things on, that was really*

*quite nice, because it was it without even knowing that's women's gym, you could tell that a lot of those things were written by women, just by what was written...and that was great. And it showed a great camaraderie between the people at the gym and, and the way that things are set up...Actually, it should be a very intimidating space, because all it is, is just weights. It's, it's nothing else. There's no nice treadmill or nice little exercise bikes, you can trundle along watching the TV. It should be a much more intimidating space, but it didn't feel like that (Joanne, Interview 1).*

Alongside discussing the physical space, participants highlighted that the way sessions were designed and delivered created a positive, relaxed and non-judgemental atmosphere. The atmosphere within the sessions, could be viewed as one of escapism, where participants felt free to be themselves and not constrained by their diagnosis, providing a sense of normality.

*You don't feel like a cancer patient when you're there... she doesn't make you feel you're here because you've got cancer (Judy, Interview 2).*

This idea of escapism was reinforced by many of the other participants, who suggested that despite cancer being the reason they had come together to attend the programme, this was not a primary focus for the session or indeed participant conversations.

*We're just really lucky that it's a nice group of people and again we've all got a common bond but we don't spend all the time talking about it (Judy, interview 2).*

*...and its not all about treatment you know, we do chat about other things as well (Anna, interview 2).*

Interestingly, whilst many shared similar thoughts regarding the escapism that sessions provided, Anna (interview 2) went on to suggest that *it's not all about the exercise* either and the sessions were *cheerful and happy*. The primary reason for participants attending had been to engage in an exercise programme but what had resulted was the creation of a space that went beyond facilitating

an exercise session and instead one of enjoyment and fun, to the point where exercise became an afterthought.

Ideas specifically regarding camaraderie are explored later in this report (4.3) but the suggestion that a supportive and encouraging atmosphere existed in the sessions was evident. Participant comments reflected how individuals supported and encouraged each other during the sessions but it was also noted that this was without competition. One participant suggested the only competition, was with herself.

*...it's been a nice environment. You know, you haven't felt sort of like you're in competition or anything like that, although I tend to be in competition with myself more than anybody else (Ellie, interview 2).*

#### **4. Programme Impact**

Data from the interviews indicated that there were a number of different ways that participants felt that that programme had impacted upon them. The type of impact varied for each person, but all participants reported that the programme impacted on them positively and spoke highly of their experiences. Some common themes emerged from the data, indicating that the participants experienced physically, psycho-social and social impacts from the programme.

##### **4.1 Physical Impacts**

When first interviewed, participants were asked to share what they wanted to achieve as part of their engagement in the programme. Many of the participants articulated that they would like to feel physically fitter or stronger by the end of the programme. At the second interviews all participants reported that they experienced some physical benefits because of the programme, this was often expressed as '*feeling fitter*' or '*stronger*'. This indicates that participants had experienced success in relation to their original goals. Interestingly at both interviews, many participants initial reference to a sense or feeling; '*fitter*' or '*stronger*' were often used without providing any further definition or clarification. When questioned further, participants articulated different ideas of what

feeling '*fitter*' or '*stronger*' meant for them. These different notions of '*fitness*' or '*strength*' were revisited by participants when discussing how the programme had impacted upon them.

Some participants commented that their bodies felt or looked different i.e. more toned, slimmer and associated this with being '*fitter*'. Others expressed that they could lift more (weights) as a result of the programme. Some felt fitter because they had more energy or endurance to complete tasks at home or engage in more leisure activities. Therefore the programme had a variety of physical impacts on participants including improved body tone, weight loss, increased flexibility, strength, endurance and mobility.

A number of participants discussed the improvements in their fitness or strength in relation to their cancer; reporting that they felt that the programme had helped them to *get back* to their pre-cancer fitness or strength. They felt the programme had enabled them to regain strength or capabilities which had been lost through their cancer journey. It was evident that some participants felt that their engagement in the programme had aided their physical recovery from cancer treatment or surgery. This included regaining physical strength, flexibility, mobility and endurance. This had then impacted upon their day to day lives in a number of ways.

*My surgery was abdominal. So when I started (the Strength in Cancer programme), my abdominal muscles were shot. And I saw my consultant in September, and he said, 'yeah, the, the abs are back'...but I noticed it quite soon into the programme without actually starting doing the weights just with the exercises we were doing. And I just noticed little things like it was I found it easier to roll over in bed, you know, because my core muscles were strengthening. And now, I just pretty much do everything I did before (Sally, Interview 2).*

*I feel so much better in myself..., it's the simplest things. Okay, like I couldn't, I've got kitchen cupboards and I've got a little kickstand because I couldn't reach the top shelf. I can now literally stand on my tiptoes and my body will stretch enough and I can just get something if it's at the front of the top shelf, shall we say. And I believe it's all because of*

*the exercises and my body is stronger, and it will do more for me (Elaine, Interview 2).*

Other participants discussed the physical impacts of the programme in relation to cancer and their future. It was felt that the fitness they had gained through the programme would enable them to be '*fitter for*' or '*more ready*' for whatever came next in their cancer journey. This was expressed by both those who were receiving cancer treatment and those in recovery.

*It's made me that little bit fitter, which is good for starting chemotherapy, again, because I started from a good place, and not a sort of low place (Ann, Interview 2).*

*It's just in case I ever need any more treatment, I'll be fit enough, I'll be fit. I'm ready for it (Sally, Interview 2).*

## 4.2 Psycho-social Impacts

All participants reported that the programme had psycho-social impacts for them. Overarching themes included participants experiencing a sense of achievement, increased self-efficacy and confidence, identity formation and regaining a sense of control.

### 4.2.1 Sense of achievement and self-efficacy

Whilst some participants had engaged in strength training previously, for many this was a new, unique and somewhat out of the ordinary experience, having never engaged in strength training before. The use of strength and specifically weight training had a significant and profound impact on some participants perception of their own strength and capabilities. This was particularly evident for those participants who attended face to face sessions which often utilised hand weights and barbells. A number of participants framed their discussion of strength training with a sense of disbelief and astonishment; they never believed *they* could do something like strength training:

*I mean, I can't believe what I'm doing. Because obviously, I'm a bit older, shall we say and I've never ever lifted weights before. And the week before I lifted 30 kilos on a squat lift, and 19 kilos on a benchpress. Now, if you told me that a year ago, I'd be going 'well I*

*don't think I could do that, I wouldn't have the confidence' (Elaine, Interview 2).*

*I never thought I'd be lifting weights (Ann, Interview 2).*

When asked to reflect why they didn't think they could do strength training, some suggested this was related to their age or gender. Some participants had previously felt accessing strength and conditioning spaces in gym environments difficult, referring to what they called '*the gym fear*'. A range of reasons for this were given, including:

- Strength and conditioning sections of gyms not feeling like welcoming spaces for women
- Fear of not knowing what to do or doing something wrong
- Fear of judgement by other gym users (both male and female)
- Body image and feeling like I do not belong in a gym
- Perception that males dominate strength training spaces

Judy and Joanne articulated some of these reasons when discussed how they felt about accessing gyms and in particular weight areas in gym settings:

*I mean, going to a gym, when you're not skinny, thin, in lycra is very off putting, perhaps not for the for the skinny people. But when you're a larger person, it just sort of you know, it just never appealed to me at all. So no, I'm not I'm not gym bunny as they call them (Judy, Interview 1).*

*Just when you've got 10 men stood around, you know watching each other...it just, uh, no, it's far, far too intimidating (Joanne, Interview 1).*

Data indicated that cancer had heightened some of these negative perceptions for participants. In addition, many participants felt added vulnerability in accessing public spaces due to the risks related to the COVID-19 pandemic. Cancer treatment and surgery had left some participants even more aware and concerned about being judged in gym environments. This concern was often in

relation to their body image, their perceived and actual physical capabilities and feeling there would be a lack of cancer specific support and guidance available in mainstream gym settings. Deborah was previously a gym user engaging in high levels of exercise and strength training prior to her diagnosis. She discusses how she felt about going back to her usual gym post treatment:

*I've got like the fear again, if you know what I mean? Of going back to the gym because I've put on so much weight. None of my old gym clothes fit me and I will be there in my husband's t shirt. So I've got all baggy t shirts, and then just and being generally unfit because, I don't know, you get a bit of a fear. Rather than marching in there knowing what I'm getting completely doing. It's more because I feel quite crushed. I mean, I've got a bit of hair that, I'm a bit bald, it's more physical appearance, I think. And generally being unfit (Deborah, Interview 1).*

Despite many participants previously feeling that strength training and gym spaces were '*not for them*' data indicated that it was the specific use of strength training within the programme that had such an impact on them. It was evident that engaging in strength training as part of the programme impacted on participants perceptions of their capabilities, confidence and their self-efficacy. Many participants' (and their family and friends) perceptions of their physical capabilities and what they and their bodies '*can do*' appeared to be altered due to their engagement in strength training:

*That's made me feel, makes me feel stronger than I thought I was. Now I made my children laugh when I send them pictures of me lifting weights. 'Go grandma' they put! I just think I have gained in confidence if you like, with, with what I'm capable of (Carol, Interview 2).*

*It's been, I've loved every minute. It's, I've been doing things that I never thought I would ever do. In a good way. Like actual weightlifting. Yeah, if you said to me two years ago, you'll be deadlifting nearly 70 kilos. I'd be like, 'no, never' (Sally, Interview 2).*

This is particularly significant when many participants previous perceptions of strength training for women were often negative. Data suggests that the design and delivery of the programme and the gym environment itself had removed these perceived barriers to strength training for the participants. This subsequently altered the participants perceptions of their own capabilities, allowing participants to build their confidence and develop a sense of achievement whilst developing their physical fitness. The programme also altered the participants perceptions of how appropriate strength training and gym spaces can be for women and women with cancer.

#### 4.2.2. Identity and Sense of Self

When reflecting on their experiences of the programme many participants commented on the ways that strength training had impacted on their sense of self and their identity. In both interviews participants discussed the ways cancer had disrupted their identity and the way they felt about themselves. Types of identity disruption were multiple and highly individualised but included disruptions to how they were able (or felt able) to fulfil their role in the family or at work, changes to their behaviour (e.g. feeling less able to be spontaneous) and their outlook (e.g. feeling more or less positive). Some of the reasons given for identity disruption included the physical, psychological and social impact of treatment and surgery, how 'cancer bodies' are conceptualised and situated in medicalised, pathogenic ways, perceptions of how you 'should behave' when experiencing cancer as well as each individual's personality, disposition and life history. It is important to note that the size and scale of this sense of identity disruption was also highly individualised. For some this was a 'blip' or relatively temporary and for others this was long term. One example of how cancer impacted on participant's identity was shared by Ann. Ann used the term '*sick person mode*' to try and make sense of her experiences of cancer, cancer treatment and its impact on her identity:

*I think when you've got cancer and whether you're having treatment, or whether you're between treatment, you don't exactly feel, it's difficult to explain, you can get in that I'm a sick person mode, if you're not careful. And I think I've slipped into it from time to time. And you tend to think 'I can't do that', you know, and I can't and I think doing this (exercise programme) makes you believe that you can do more (Ann, Interview 2).*

For Ann, the programme had provided an opportunity to get back a sense of normality. Being able to engage in something that was so different to everything else in her life, which was cancer related, had had a profound impact.

*You're, you're doing something for yourself (exercise programme) that you thought you couldn't do. And it's the word normal again, it just makes you feel a bit more like a normal person and not just this sick person. It's another almost like another appointment a week, each week, that's a nice appointment, and not a doctor's appointments and things. I think the programmes really helped, it's made, it makes me feel that I'm a bit normal. You know, it's not all about the treatment and the cancer, it's doing something else, for me and being well not being with but virtually being with other people. And it's, it's cheerful and its happy (Ann, Interview 2).*

Ann was not alone here. Many participants felt that the programme had positively impacted on their sense of self. The programme increased participants feelings of 'normality' and helped some redefine their identity (away from cancer) and changed their perceptions of what they felt they 'can do'. Sally felt empowered by her experiences of 'lifting' and highlighted how it had become part of her identity.

*I think it's boosted my confidence a lot. You know, and, like, all my friends know that I do it. And they're always asking me, you know, 'oh what have you been lifting this week?' It's just the confidence in, you know, and just because I'd never thought that I would ever be weightlifting and enjoying it. I have got something to talk about... it's that confidence thing it's you know, I'm doing something that I don't know anyone else that does it. Yeah. You know, I'm doing something that nobody else I know does (Sally, Interview 2).*

*I don't know, its just made me think, you know, you can do whatever, you can do whatever you put your mind to. Anything. And I am doing other things that are sort of like out of my comfort zone as well. Now, I even like ran the other day. Yeah, just little things like that (Sally, Interview 2).*

It is important to reflect upon these feelings of '*I can do*' alongside how cancer had left many participants feeling that they '*can't*' or '*shouldn't*'. Ann reflected on how her experiences on the programme had shifted her perception of what she could do, whilst undergoing treatment:

*You tend to sort of give in and think I can't do anything, I feel so dreadful. I mean, this morning, I didn't feel great at all, when I got up and there's a little newspaper shop sort of just around the corner from us. And usually walk with my husband most days...and he said, it's three quarters of mile there and back is three quarters of a mile...and I, just looking back to before the programme, I'd probably not have done it, I'd probably just thought I don't really feel great, so I'll just rest. And instead of just wanting to rest all the time now I find I'm even doing more around the house, because I'm thinking 'I can do it'. And the more you do, I think the more you're able to. I know that there's going to be days, when I'm, when I can't. But I think it helps me to accept those days, and then get back on it straight away afterwards (Ann, Interview 2).*

Therefore, data suggests that for many participants the confidence, sense of identity and feeling '*I can do*' which had developed through engagement with the programme had transferred to their wider lives. This type of impact varied from participant to participant but a number expressed feeling a 'buzz' or 'high' which impacted on them long after the sessions had ended:

*Definitely I always finished on Wednesday or Thursday and always felt more energised...it gives you a boost, it's those endorphins. The first time I picked up the bar with a weight so I'm I came home knows and I was buzzing, I said 'you'll never guess what I've done?' and he said 'you haven't?!" I said 'I have, I have done a weight!' (June, Interview 2).*

The 'buzz' participants experienced had an impact on other activities and their daily lives. For example, feeling energised to tackle household tasks or going out to engage in further physical activity i.e. walks or gardening. Interestingly, some participants articulated that it was specifically the experience of strength training and lifting weights which created the buzz for them:

*I mean, at the end of the session, I feel exhilarated and it's like, 'oh, yes. Check me out, I can do it.' I suppose it's because it's something that you, none of us could ever have imagined ourselves doing? Let's, I mean, let's just say I went along to a, like a Pilates class or something like that. I probably wouldn't get that same buzz. Because I think lifting weights is oh, it's just something so different and out of like, my comfort zone. And it's good to know that you can do things that you didn't think you possibly could. And I think that's what gives you that high when you leave the session (Elaine Interview 2).*

Sally and Elaine both felt that the programme had developed their confidence and identity in such a strong way it was impacting on their career choices and work life.

*I gained confidence that actually, I can do stuff that I probably didn't think I could do. It made me reflect on my current job, where I would like to reduce my hours from four days to three days... I need more time to myself to do the things like the gym, the strength training. It has in that respect because I probably wouldn't have thought about that if I hadn't done the programme, you know? But yeah, I mean, like I say, I feel so much better when I'm doing the exercise and when I'm at work, sometimes it's like, 'oh, gosh, why am I dealing with all this stress? Do I really need it?' (Elaine Interview 2).*

*Even just like down to getting this job. With my medical history, I just, it was like, no, no one's ever going to employ me, but I think because of the programme and the confidence, I just went there in a complete with a completely different attitude. You know, it's like, yeah, 'I'm going to get this job. I am going to do this'. So, so it's things like that as well. Yeah, I think it's impacted my whole attitude towards everything (Sally, Interview 2).*

#### 4.2.3. Sense of control and power

One of the ways that cancer had impacted on some participants was related to how their bodies were situated and treated as part of their cancer treatment or surgery. A number of participants felt a lack of control and power, at times they felt somewhat detached from their bodies throughout

their cancer journey. The programme provided an opportunity to regain control and power over their bodies, which had been lost through their cancer treatment. Joanne who was undergoing cancer treatment during the programme articulates this.

*Often on when you have cancer, you turn up and people do things to you, you actually get very little say, in what what treatment you have, how you have it...I just wasn't given that choice. I was, it was taken away from me, I was told that's what was happening and that is often what happens when you have cancer is that you don't have any choice. Decisions are made about you. And then you're told what's happening. And, and if you can control a bit of it, like the Strength in Cancer programme, you can then yeah, it just makes life a little bit easier...I thought, yeah, let's, let's do this and then I can control this and I can do this (Joanne, Interview 2).*

Quite often participants expressed that the programme was an opportunity to do something '*for them*', something that was not related to cancer. This further suggests that engaging in the programme enabled participants to regain control and power over their bodies and lives.

#### 4.3 Social Impacts

A number of themes emerged from the analysis that indicate that the programme had social impacts for the participants. Social impacts were present in both the online and face-to-face sessions groups but were more prominent for those who were able to attend the gym. As discussed in 3.5, participants reported that sessions were enjoyable due to the delivery style, structure and atmosphere that was created. Sessions were described as supportive and non-judgemental.

*We all encourage each other. You know, when we do 'cmon you can do it, you can do this one, you can do it'. And the camaraderie between, you know, the girls and Rachel is just, yeah, priceless to me. Getting emotional now (Elaine, interview 2).*

*I thought it might bother me being watched because we were quite a nice group. And, you know, because I think, you know, I've always been a bit body conscious and, you*

*know, wearing gym gear is totally out of my comfort zone. There's just no judgement. No, you know, we were just a really good team (Sally, interview 2).*

The support and camaraderie from other group members helped participants gain that sense of achievement as reported in section 3.5. Group members all having experiences of cancer created a common ground, with some participants finding it reassuring to know that others in the group had a shared understanding of their experiences. Some participants enjoyed the opportunity to meet (either online or in the gym) other women with cancer:

*It's nice to be able to talk about cancer to people that have actually experienced it. Because I know there's a lady on our, on our, in our session that's had the same cancer as me. So we've had the same treatment and so it's nice to be able to talk to her because she, we, we've both been through the same thing. We know what we're talking about (Sally, interview 2).*

*Sometimes you do still want to talk about it, sometimes you are still affected because every joint in your body aches and your scars are pulling and you know you're not entirely happy with the way that your hair is growing back, even though you are happy that your hairs growing back, if that makes sense. So, all of those like sort of little things but because you've got somebody, you're with people that have had similar and shared experiences, it's kind of, you, you don't feel alone, if that makes sense? (Alison, interview 2).*

This feeling of shared experiences appeared to strengthen the bond between the women in the group and further aided participants ability to engage in the sessions without fear of judgement.

*Because there's others there as well, we all, we all encourage each other. You know, 'C'mon you can do it, you can do this one, you can do it'. And the camaraderie between, you know, the girls and Rachel is just, yeah, priceless to me. Getting emotional now (Elaine, interview 2).*

Aspects of the programme design and delivery seemed to facilitate the strong links between participants. This included:

- Women only groups
- Small group size
- The support and facilitation by Rachel
- The relaxed environment
- Time made available to talk in sessions

Despite participants valuing that it was a cancer specific programme, data also indicated that some participants liked that the sessions were not all about cancer, or as Claire referred to it as not being too 'cancery'.

*But it's not all it's not all doom and gloom 'oh, dear me, I've got cancer, you know, it's just right (Judy, interview 1).*

*'I did think' Ah it's gonna be all cancer, cancer cancer!' and I want something for me. But I thought I don't want it to be all cancery but, having other ladies there and talking to them, it was nice (Claire, interview 1).*

Claire further reflected, despite her not wanting cancer to be the focus of the sessions, she valued the opportunity to connect with others who had cancer and who had different cancer experiences to her own.

*Yeah. It was one of the ladies, she's very, she's a lot, she's at stage four cancer, which scares the shit out of me. But actually, I thought she's at the gym, she is going to the gym. She is doing all this exercise. It's brilliant. Even, so stuff like that it kind of makes you think yeah, you know, I can do this. Helps you kind of process things, I suppose, and perceptions (Claire, interview 2).*

This opportunity to observe others with cancer engage in strength training further impacted on some participants perceptions of what bodies with, recovering from, or living with cancer could achieve. The opportunity to watch and support others in the group without judgement appeared to be a powerful aspect of design of the gym-based sessions. This in turn impacted on participants perceptions of what *they* could do or achieve in a number of ways. These included:

- Taking an active role in their cancer journey
- Valuing the importance of fitness and strength in their lives
- Valuing the importance of fitness and strength for cancer treatment and recovery

Elaine articulated some of the different ways her perceptions of her body and its capabilities had altered as a result of her engagement with the programme.

*I respect my body more now. and know that I need to keep fit and strong for whatever it may come around the corner. Next for me to fight with, so I feel like now my body is stronger. And yeah, I'm working with the immunotherapy I had and I realise that I need to do everything to keep myself strong and to keep up the fight...I am fighting back against it because I'm like, I don't want to go anywhere just yet. I'm gonna keep fighting and the strength training as given me that fight back in my body (Elaine, interview 2).*

*And we went to Arran in September, which we have been once before with friends. I climbed up you know Glens and little mountains...I did quite a lot of stuff there that I wouldn't have normally done. I'm quite scared of heights. And my friends were like, 'oh, go on, you can do it. You can do this'. And I did. And I did it....I'm doing stuff now that I wouldn't have done (Elaine, Interview 2).*

## **5. Barriers**

Data indicated that 66% of participants remained engaged in the programme for the 26 weeks suggesting that there were some barriers to programme adherence. Qualitative data indicated many of the barriers participants faced were external to the programme design and delivery. The main barriers participants faced were related to practical issues, such as travel, work, family, other commitments or cancer treatment. 76% of participants were undergoing some form of cancer treatment during the programme, some sessions were frequently missed due to appointments or experiencing side effects of medication.

Qualitative data indicated that providing online classes aided recruitment and removed barriers for those who would not have been able to travel to the gym to attend sessions. Offering the opportunity to switch to online classes enabled some participants to continue to engage in the programme when they experienced challenges (e.g. attending appointments or looking after children) in attending face to face sessions. This flexible approach to attendance was particularly valuable for individuals who were undergoing cancer treatment during the programme.

## **6. Conclusions and Recommendations**

The aims of this evaluation were to:

1. Assess service uptake, accessibility, adherence and attrition over the 26-week programme, comparing online and in-person streams.
2. Assess perceptions of strength training as a woman, and as a woman with cancer, including how this changes over the course of the programme.
3. Assess how perceptions of being 'strong' influence the cancer recovery journey.

In addressing these aims, analysis of both key programme data and semi-structured interviews has demonstrated that:

- Attendance at the programme was good overall but easily impacted by ill health, cancer treatment, personal commitments and the Covid-19 pandemic

- Promotion via the Lincoln Cancer Support Group Facebook page attracted the most interest by programme participants
- Attendance positively impacted on levels of fatigue, anxiety and depression experienced by the participants
- A personalised, individually tailored approach to programming alongside the role of the instructor was key in providing a positive experience
- Participants' perceived benefits from participating in the programme included:
  - o Physical: improved body tone, weight loss, increased flexibility, strength, endurance and mobility
  - o Psycho-social: a sense of achievement, increased self-efficacy and confidence, identity formation and regaining a sense of control
  - o Social: exercise without fear of judgement, camaraderie, meet and connect with others who had cancer
- Additional impacts were noted for those participants who attended face-to-face in comparison to online delivery
- Online delivery uniquely offered participants the ability to be flexible around other commitments and the need to travel
- The programme exceeded participants expectations, even if they unsure as to what the programme may involve
- Participants experienced very few, if any, barriers in accessing and attending the programme

As is evident from this report, the Strength in Cancer project was well received by participants and has been highly successful in a number of ways, as detailed above. The programme participants did share some ideas to consider for future iterations of the programme.

### **Recommendation 1**

Some participants suggested that they would like more opportunities to engage in strength training outside of sessions. They valued the online resources that they received, and some participants said they would like more at home resources. There is of course a need to ensure that participants adopt a frequency of physical activity that is appropriate for their fitness levels and their cancer journey.

**To consider providing a summary sheet of exercises that participants can complete at home.**

### **Recommendations 2**

Participants whose engagement in the programme was disrupted by cancer treatment felt restricted by the 26 week duration of the programme. Participants felt that if the programme was continuous, they could re-join the programme once their treatment had ended or their health had improved.

**A continual or rolling programme structure would help participants to access more sessions over a longer period.** However it is recognised that this is not currently possible due to the nature of the project funding.

### **Recommendation 3**

Whilst it was evident that participants experienced social benefits from the programme engagement, participants reported they would welcome further opportunities to socialise with others. Participants did recognise that face-to-face social opportunities were not possible due to the COVID-19 restrictions.

**To consider additional ways participants could socialise and connect outside of sessions both virtually and face to face.**

### **Recommendation 4**

One participant suggested that they would welcome some guidance and advice on nutrition. Although this is not an aspect of current provision at Darkside Rising CIC it could compliment the Strength in Cancer project.

**To consider the scope for providing nutritional guidance as part of the Strength in Cancer project.**

## 7. References

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