

Macmillan Get Active, Feel Good Physical Activity Programme

Final Evaluation Report

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On behalf of:



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1.0 Executive Summary

The purpose of this report was to examine data collected by Lincolnshire Sport and the University of Lincoln in relation to the implementation, impact and receipt of the Lincolnshire GAFG programme. The primary findings are summarised below.

In relation to the reach and efficiency of the programme (including uptake, adherence and attrition) it was evident that during the first 24 months of the GAFG programme:

- 193 individuals had attended the initial screening and 53 had reached 12months on the programme.
- Participants had an average age of 63.5 (± 15.9) and were predominantly female (54% female, 46% male).
- Whilst the sample was incomplete, 34% of participants who accessed the service considered their cancer to be stable.
- Patterns of referral had remained relatively consistent from 12 to 24months of the programme with the majority of referrals coming from LN2 and PE21.
- New referrals were noted from the following geographical areas; PE32, PE24 and PE6.
- More males than females dropped out of the programme, this was most pronounced between 9-12months.
- Those who dropped out of the programme were from the most deprived areas.

For the impact of the programme it was evident from the quantitative data that significant findings were:

- Participants reported their mobility and ability to walk had improved up to 9months of the programme.
- The number of participants who reported no issues regarding self-care increased up to 9months of the programme.
- Participants reported that they had no problems performing usual activities increased up to 9months of the programme.

- Mobility, self-care and ability to perform usual activities all declined between 9-12months.
- Participant's perception of pain decreased over the 12month programme.
- The number of participants who reported feelings of anxiety and depression decreased over 12 months.
- Participant's perception of health improved over the 12months, from 56% at baseline to 83% at 12months.

In relation to the perceptions of the programme and the guidance received it was found that both participants and stakeholders:

- Recognised and valued the client-centred approach adopted as the GAFG model. It was felt that this approach was most appropriate to those who had experienced cancer or were recovering from cancer. In particular the following themes emerged from the data as a being valued and unique elements of the programme:
 - Practitioners truly knowing the participant as an individual, through investing time in face to face appointments
 - Offering a different kind of support that is highly relevant to those with cancer or recovering from cancer
 - Practitioners knowing when to guide, motivate or give space
 - Use of technology including: tablets for Macmillan Physical Activity Practitioner (MPAP) meetings, email and text support.
 - Providing the programme at the participants home
- Felt that the time of access or referral was key to the individual.
- Reported that the programme filled a void in current cancer support and physical activity provision.
- The GAFG programme design and approach enabled participants to reflect upon the changes they wished to make to their lives through engagement in motivational interviews and participant led discussions.

- The approaches used within the GAFG programme allows the MPAPs to respond to the individual's cancer journey and changing narrative.

The stakeholders interviewed acknowledged the following potential barrier to the programme's expansion:

- The continued viability of a time intensive, client-centred approach should the programme increase the number of referrals or expand its geographical reach.

In relation to the impact of the programme, including how the GAFG programme influenced how participant's perceived and managed their cancer, the following was reported:

- The majority of participants demonstrated restitution narratives and were able to utilise the programme in order to rebuild themselves and regain the pre-cancer identity.
- Some participants articulated quest narratives and utilised the programme to improve or begin to transform themselves and their identity.
- For both sets of narratives, the aspect of identity participants sought to regain varied from individual to individual but included:
 - The physical self: strength, mobility or body image (including regaining and losing weight)
 - The psychological self: confidence, motivation and mental strength
 - The social self: the desire and ability to socialise
- A small number of participants articulated chaos narratives and at that moment in time, felt a degree of lost hope in relation to their cancer. Whilst participating in physical activity was perhaps overwhelming for these individuals, the GAFG programme was still seen as a future resource from which they could (at a later point in time) utilise to begin to rebuild themselves.
- Participants and stakeholders reported that the GAFG programme enabled them to regain control by offering an experiences (i.e. physical activity) which is the opposite of cancer and cancer treatment.
- The control gained through the GAFG programme transferred into other aspects of the participants lives, for example work, family, social life and thus impacted on their independence.

- Participants and stakeholders reported that the GAFG had allowed them to regain the confidence they had lost through cancer.

2.0 Evaluation Overview

This two year research project aimed to examine data collected by Lincolnshire Sport and the University of Lincoln in relation to the implementation, impact and receipt of the Lincolnshire Get Active, Feel Good (GAFG) Physical Activity Programme. The specific aims of this research were:

1. To assess reach, efficiency and impact of services amongst providers and partner organisations, and to ascertain the degree of potential culture change within these organisations, including perceptions of the value of the programme.
2. To assess perceptions of service provision amongst service users with cancer in the county of Lincolnshire over an 18 month period and to assess service uptake, adherence and attrition through this period.
3. To assess participant perceptions of the guidance received, together with reflections on their embodied experiences of physical activity during their engagement with the programme.

In order to assess these aims, the following methods were utilised:

- Analysis of participant physical activity data obtained via the Macmillan Physical Activity Questionnaire battery. This included:
 - Socio-demographic data
 - Minutes of physical activity achieved
 - EQ-5D-3L including state of health scale
 - FACIT fatigue scale
- Thematic analysis of semi-structured stakeholder interviews
- Narrative analysis of semi-structured participant interviews

This report examines data collected during the first 24 months of the programme. This included:

- Structured stakeholder interviews (conducted at 12 and 24 months)
- Semi-structured interviews with participants (conducted at 0, 6 and 12 months)
- Macmillan Physical Activity Questionnaires (conducted at 0, 3, 9 and 12 months)

Prior to the programme commencing, a programme theory was produced (see figure 1.1). This document was based upon available documentation describing the programme, and upon interviews conducted with key programme staff. The programme theory (figure 1.1) explicated programme goals and objectives, programme boundaries and a logic model representing the desired, logical development and impact of the programme over the short, medium and long-term (included below). This programme theory provides the basis upon which the subsequent methods-driven programme evaluation (Rossi et al, 2005) is built.

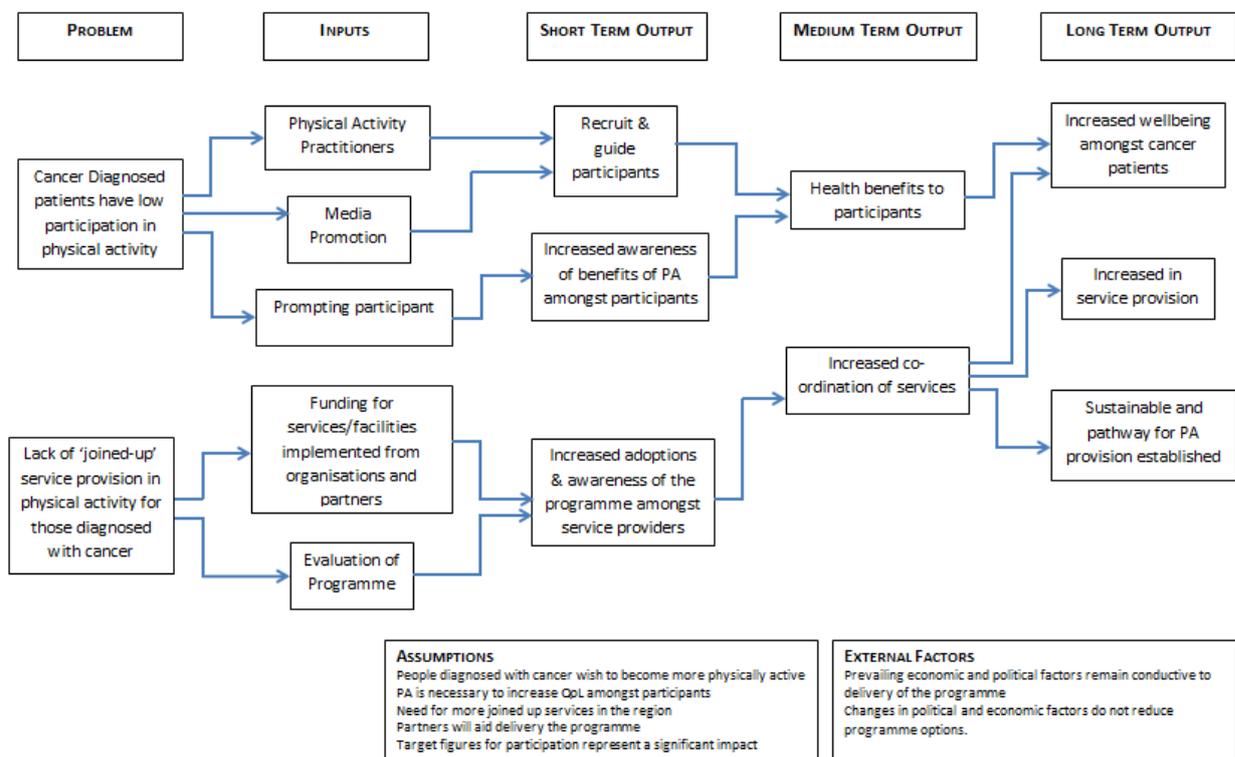


Figure 1.1 Macmillan Get Active, Feel Good logic model

2.1 Quantitative Data

Participants accessing the GAFG service were required to complete a physical activity data collection form that was devised by Macmillan. The form included a series of validated tools including; EQ-5D-3L, SPAQ, FACIT questions as well as the total physical activity time and level of sport. In addition to baseline data, all participants were required to complete the form at 3, 6, 9 and 12 months as per the Macmillan guidelines. All data collected was recorded via an online platform which enabled live reporting for the monitoring and analysis of data. For the purpose of this, evaluation data sets for each participant were downloaded in the form of spreadsheets to allow analysis.

Data were primarily categorical, which have been explored using frequency counts and percentages for each category and across primarily the 6 visits (i.e. screening, months 0, 3, 6, 9 and 12). In some instances the distribution of patients across groups was uneven or resulted in small counts in some groups. In these situations the data could not be explored across combinations of variables, and as such just the frequency counts and percentages are reported for the variable alone (e.g. ethnicity). Where data are continuous, means and standard deviations are used to describe either the variable alone or across variables (e.g. across visits).

2.2. Qualitative Data

A method of purposive sampling was used to identify participants for both stakeholder and participant interviews. This was achieved through the use of the Macmillan Physical Activity Practitioners (MPAPs) who acted as gatekeepers, identifying individuals for interview from their known contacts. This ensured that those interviewed had suitable knowledge and experience of the service and therefore were able to provide relevant and meaningful data that would fulfil the research aims (see section 2.0).

Initial contact was made with both stakeholder and participants via email or telephone. Those who responded with interest were subsequently interviewed. A semi-structured interview guide was used in both cases. The interview guides contained broad themes and questions to be discussed but allowed for some flexibility during the interview process.

All interviews were recorded using a Dictaphone and then transcribed verbatim. Seven stakeholders were interviewed once during the first year of the programme and eight additionally during the second year. Interviews with stakeholders were on average 21 minutes in duration. Eleven participants of the GAFG programme, with a mean age of 58, were interviewed at three time points during their involvement with the programme (during 0-3, 6-9 and 9-12 months). One participant was interviewed at two time points (during 0-3 and 6-9 months), as they did not respond to invitations to interview during phase 3. Interviews with participants were on average 48 minutes in length. Data from stakeholder interviews were analysed inductively through thematic analysis. Thematic analysis is a process by which key themes within the data are identified, analysed and reported (Braun and Clarke, 2006; Bryman, 2008). Raw interview data was first sorted into a series of initial codes. These codes were subsequently analysed in order to identify any common patterns. Codes were then conceptualised into broader themes or categories in order to identify any underlying relationships, connections or linkages between codes (Bryman, 2008).

Data from participants on the GAFG programme were analysed through narrative analysis. Narrative analysis, takes the stories and the way they are told by individuals as its primary source of data and examines the content, structure, performance and the context of the story or storytelling as a whole (Sparkes and Smith, 2014). In narrative analysis the primary interest is not directly on what is said within a story in relation to the content, the language and telling itself is also examined alongside the environments that give shape to narrative content, structure and performance (Frank, 1995) Reissman, 2016; Sparkes and Smith, 2014). Therefore through using this type of analysis, researchers can examine core patterns of the narratives by

looking at the content of the stories, identifying key themes and interpreting the life stories to help the researcher understand the information and the meanings behind them (Sparkes and Smith, 2014). This process then enables the researcher to compare and contrast between all of the individuals narratives within the study, thus after reading through each narrative, highlighting themes, making conceptual comments and interrelating themes, it is possible for the researcher to compare and contrast the most meaningful themes, which results in redefined themes (Sparkes and Smith, 2014).

3.0. Key findings

This section considers the quantitative data which identifies the reach and impact of the GAFG programme. In doing so, it also determines the programme uptake, attrition and adherence. Therefore it addresses elements of research aims 1 and 3 (see section 2.0).

3.1. Programme Reach

In line with the original research aims of the evaluation it was necessary to identify the reach of the GAFG service, who was accessing the service, from where and how effective this was. In collating the data it was possible to determine the attendance of participants, 193 attended the initial screening and of this 11 were deemed ineligible for the service by the MPAPs. At 12months 53 participants had completed the GAFG programme, with the remaining still engaged in the programme. The data also provided some insight into who was most likely to access the service.

The data highlighted those key elements that defined a typical participant who accessed the GAFG programme. The average age of the participant was 63.5 (± 15.9) and predominantly female (54%). The type of cancer participants were referred with ranged greatly, however the highest frequency was colorectal (25%) and breast (24%) cancer. The status of the participant's cancer was a question added 14months after the start of the programme however of the responses that were collated identified that the majority (34%) classed their cancer as stable, meaning it was neither decreasing nor increasing.

Of those accessing the service it was important to note whether these characteristics were related to participant attendance over the 12months. Adherence and attrition is determined by participant's attendance at meetings with their MPAP at baseline, 3, 6, 9 and 12months. Age appeared to be unrelated to

this attendance however gender did. In comparison to women, more men dropped out from the GAFG programme with the biggest decline occurring between 9 and 12months as show in figure 3.1.1.

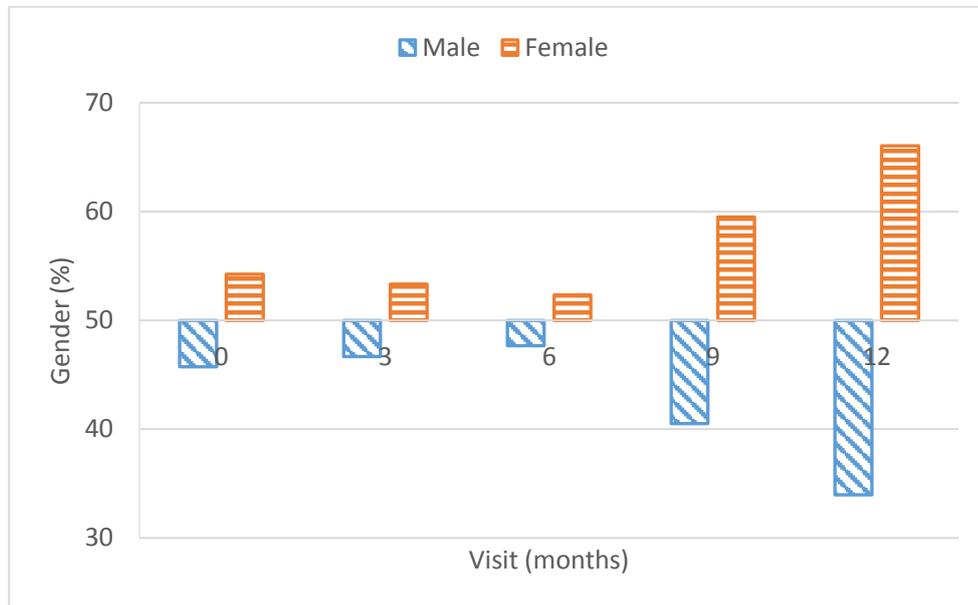


Figure 3.1.1 Frequency of male and female attendance at baseline, 3, 6, 9 and 12months

There was also some pattern to data when the type of cancer was considered. As figure 3.1.2 demonstrates, the greatest drop out was observed for those participants with prostate cancer however the least drop out was identified as being those participants referred with either neck, lymphoma or breast cancer. It would have been interesting to have related this to the data concerning cancer status however due to the insufficient sample size this was not possible.

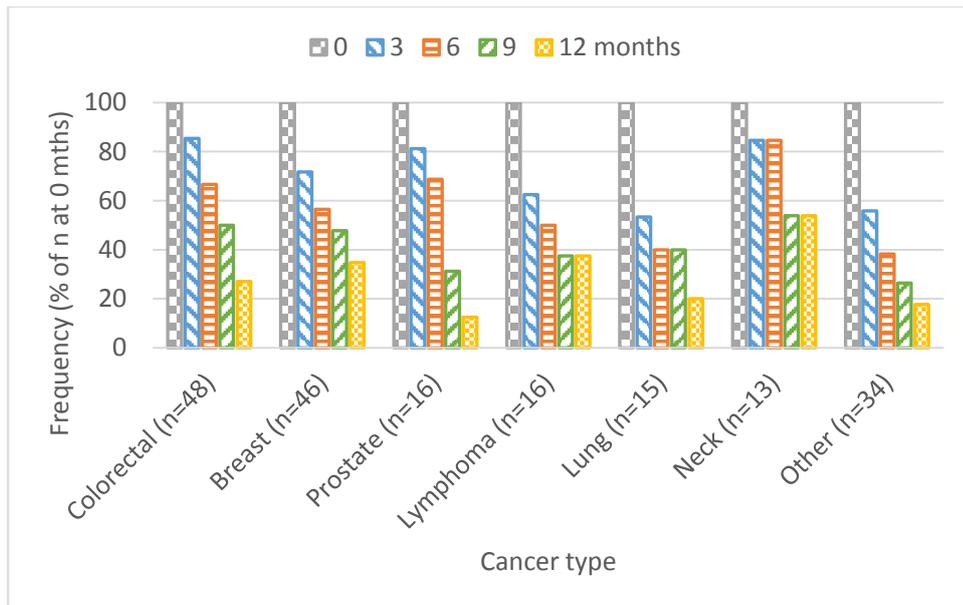


Figure 3.1.2 Frequency of attendance in relation to type of cancer

Data collated on deprivation highlighted issues regarding continued attendance. Deprivation is represented by a score between 1 and 10, 1 being the most deprived and 10 being the least deprived. The mean deprivation score increased at each of the time points (as shown in figure 3.1.3). This indicated that those who remained in the programme were least deprived and those who had dropped out were the most deprived.

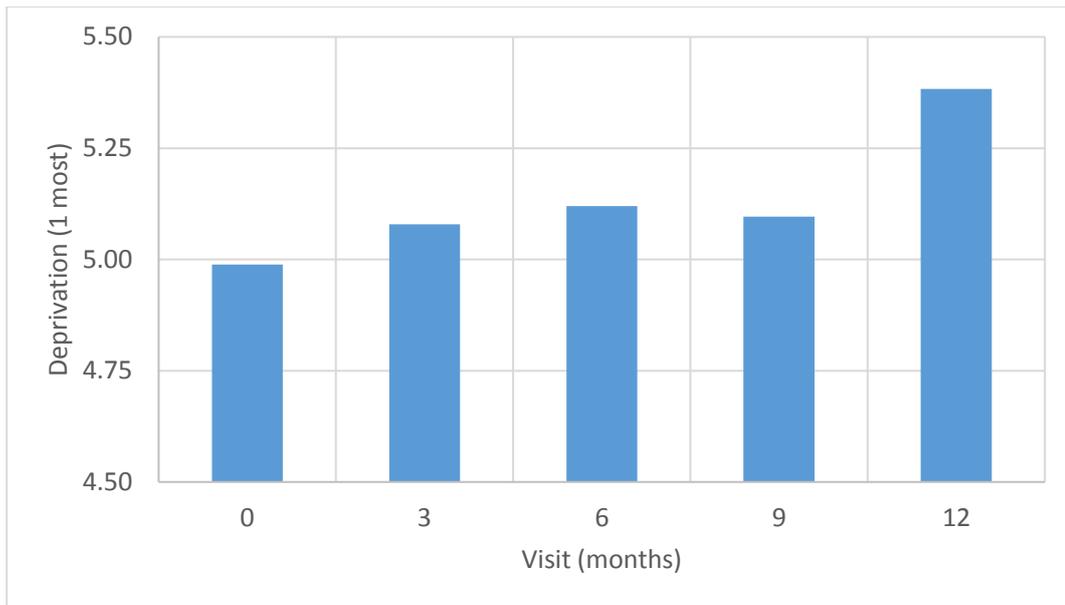


Figure 3.1.3 Mean deprivation score of participant attendance at baseline, 3, 6, 9 and 12 months

For those referrals made, it was possible to note where the referrals were initiated from. Of the geographical area covered by the MPAPs the majority of the referrals were made from LN2 (10%), PE21 (8%) and equally LN6, PE11, PE22 and NG31 (each 7%). The top two referring postcodes, LN2 and PE21 were the same postcodes that were identified in the interim report. It is also worth commenting that those postcodes showing referral numbers that were slightly above average previously, had continued to grow and were now jointly positioned in the third highest referral areas within the county. Five areas had shown no growth since the interim report, these were; LN7, LN13, NG23, NG32, DN21, DN36 and S7. In contrast to this three new postcodes were identified in relation to the data evaluated in the previous interim report PE32, PE24 and PE6, suggesting there had been some progression in the reach of the programme.

When considering this data, there had clearly been further expansion in the reach of the GAFG programme since the interim report. This was perhaps best captured geographically when considering the postcodes from where referrals were made and the volume of referrals. The typical participant accessing the service had seen little change however, with a predominance of the over 60 female. A range of cancers were represented however what was perhaps more insightful was the stage of cancer when the participant as

referred. Although this was a question that had been introduced later by Macmillan it was interesting to note the higher volume of participants at the 'stable' stage of their cancer journey. This may warrant further investigation, to explore whether this decision is patient led i.e. they decide that this is the most suitable time for them to access the service or whether those making the referral have made that decision. Either way this would be likely to influence the individual's experience of the GAFG programme. Finally, the higher rate of drop outs from those most deprived was highlighted. This is interesting as many of the activities suggested by the MPAPs require little if any cost, therefore it is unclear as to what may be the cause of this.

3.2. Programme Impact

By reviewing the responses to the questions asked, within the Macmillan physical activity questionnaire form, at each of the given time points it was possible to gain some insight into the impact of GAFG. Particularly, focus was made upon how this developed between baseline and 12months. Although a number of questions could have captured this, the data that demonstrated significance were those questions that collated participant's total time active and those that reflected on participant's perceptions of their overall quality of life. The first five questions followed a simple scale which required participants to indicate whether that had either; no problems, some problems or extreme problems for the given area of question. The sixth question followed a different format with a scale of 0 to 100, 0 being the worst and 100 the best. The following section reflects on these responses.

Participants were asked to recall the minutes they spent active. Values indicated that for those participants who had completed 12months their activity levels outside of work had continued to increase throughout the 12months, as shown in figure 3.2.1. Participant's total minutes active during leisure time had all increased, this included; walking outside, manual labour outside of work and sports training. This meant that

participants were actively increasing their leisure time physical activity throughout their 12 months as part of the GAFG programme, which indicates a notable behaviour change.

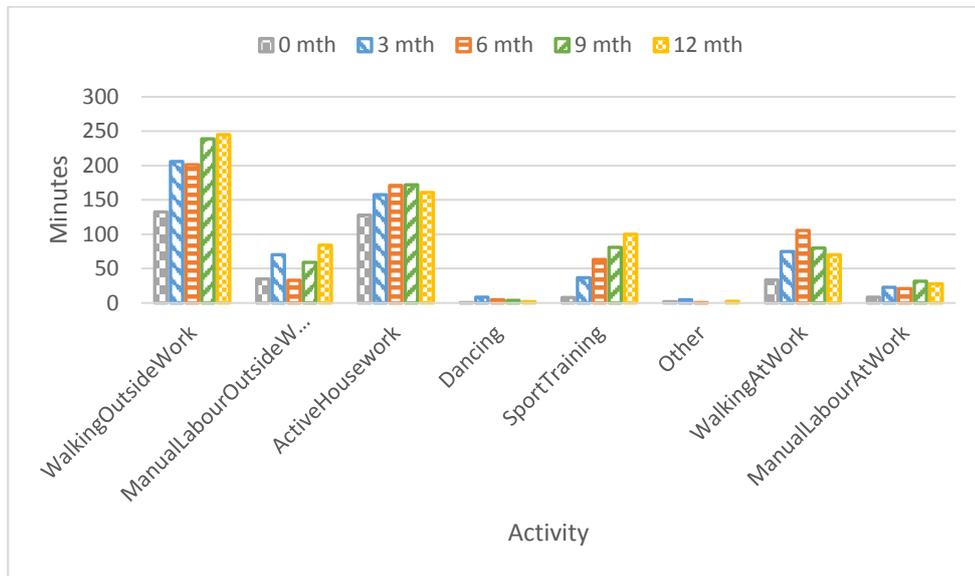


Figure 3.2.1 Participants total minutes active

Participants were required to reflect on their mobility and whether they experienced problems walking. Scores demonstrated that any problems walking generally improved over 12 months. For those who identified that they had 'no problems walking about', this increased at 0 to 3, 3 to 6 and 6 to 9 months (see figure 3.2.1). Each of these increases were identified to be significant. There was however some decline at 12 months by 6%.

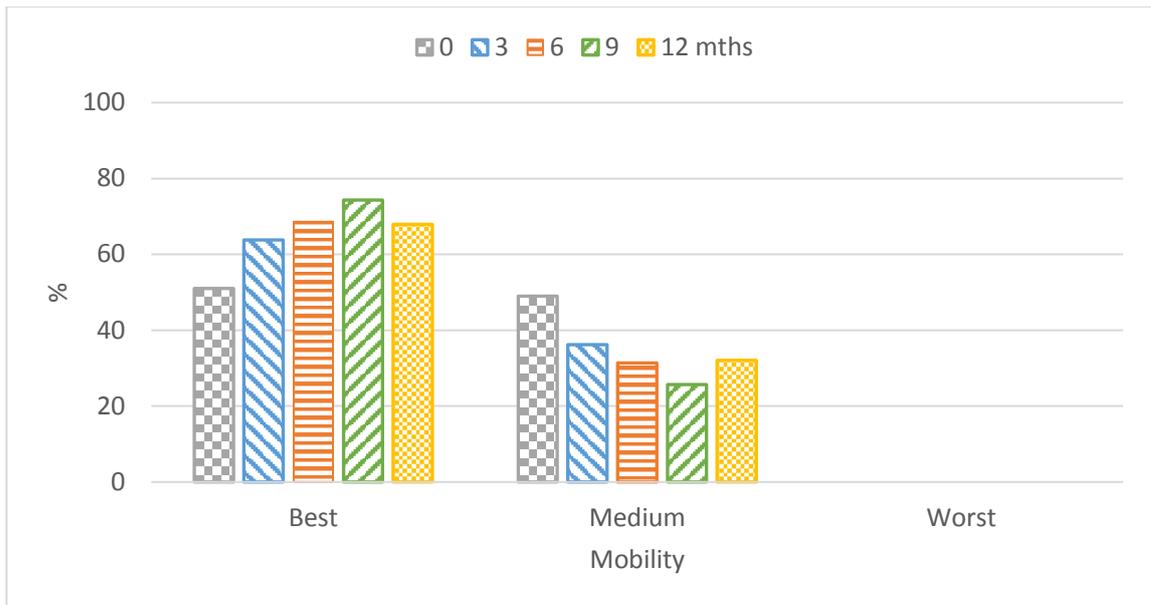


Figure 3.2.2 Participant responses regarding mobility at baseline, 3, 6, 9 and 12months

The concept of self-care was explored, asking whether participants experienced problems performing typical daily tasks such as washing or dressing. Participant responses indicated that having no issues regarding self-care increased between 0 to 3 months and 6 to 9 months (see figure 3.2.2). This however was in contrast to declines at 3 to 6months and 9 to 12months.

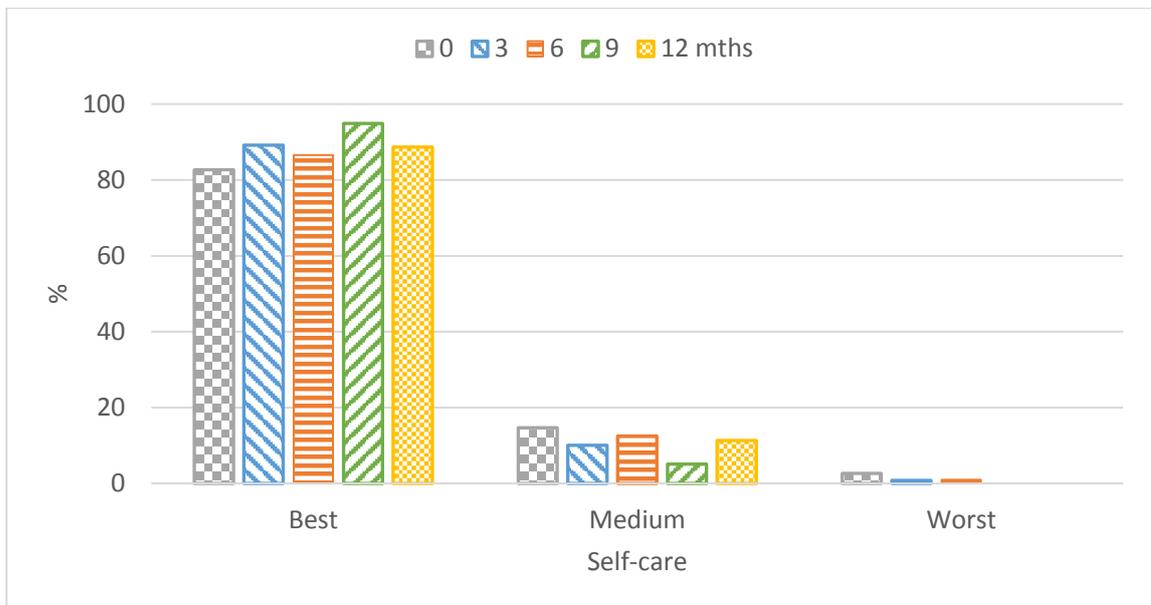


Figure 3.2.3 Participant responses regarding self-care at baseline, 3, 6, 9 and 12months

Participants were asked whether they experienced problems performing usual activities, these included; work, study, housework or other family and leisure activities. The percentage of participant's that perceived they had no problems in performing their usual activities improved from baseline at 3, 6 and 9months. There was a small decline of 10% however at 12months.

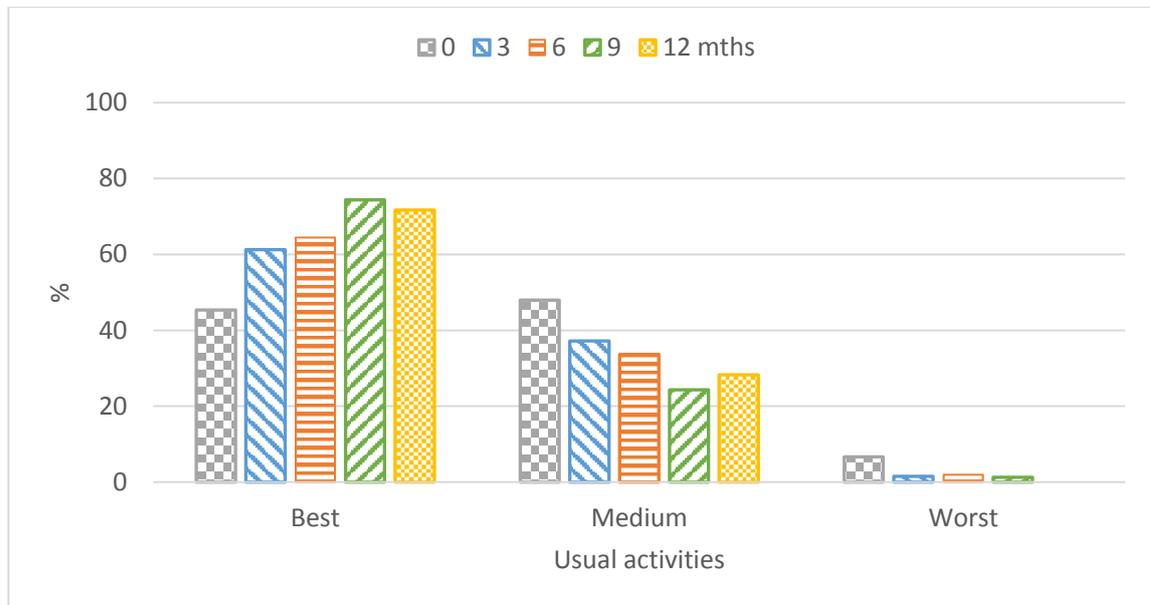


Figure 3.2.4 Participant responses regarding usual activities at baseline, 3, 6, 9 and 12months

The issue of pain/ discomfort was examined by establishing whether participants' had experienced no, moderate or extreme pain on that particular day. Participant responses identified that their perception of the presence of pain decreased over the 12months. The percentage of participants who indicated that they had 'no pain or discomfort' continued to increase at each time point with a total of 76% at 12months.

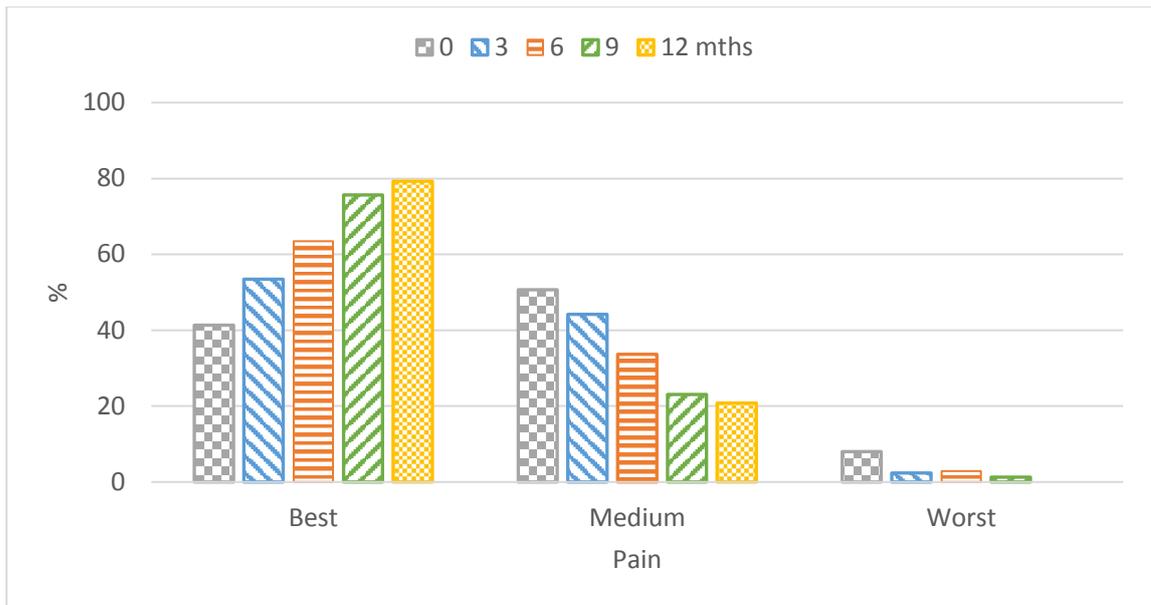


Figure 3.2.5 Participant responses regarding pain at baseline, 3, 6, 9 and 12months

Participants were asked whether they were experiencing anxiety or felt depressed. Participant responses indicated that the percentage of those who did not feel anxious or depressed increased over 12months. The biggest increase was observed between baseline and 3months, increasing from 48 to 71%. Small increases continued to be observed up to 9months at 87%, where scores then plateaued for 12months.

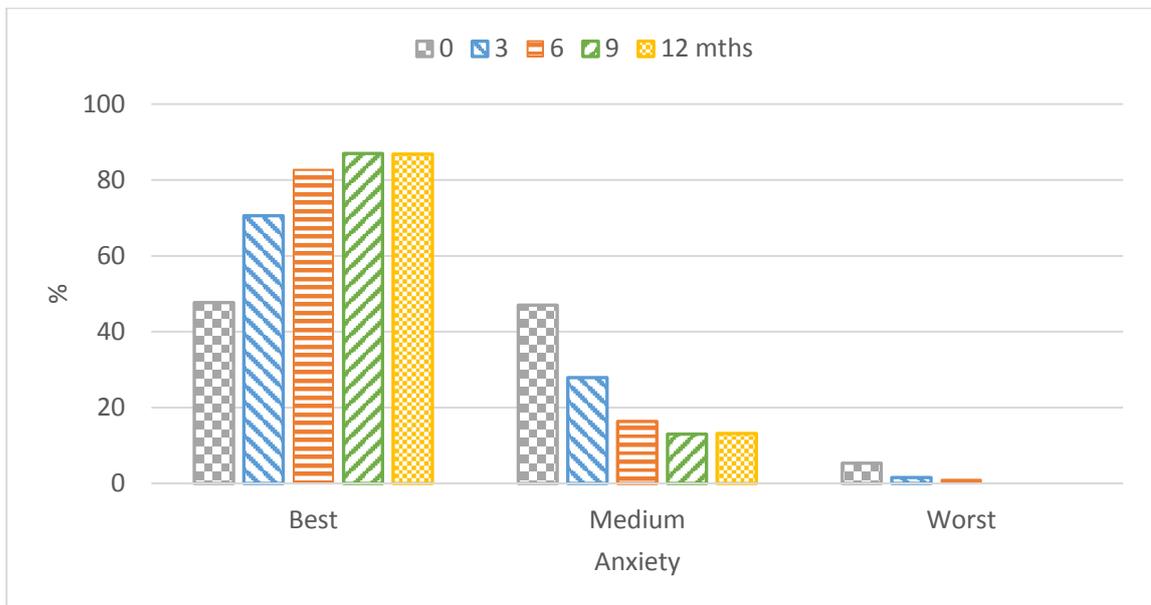


Figure 3.2.6 Participant responses regarding anxiety at baseline, 3, 6, 9 and 12months

In determining participant's state of health, participants were required to indicate how good or bad they felt their health was on a scale between 0 and 100, with 100 being the best imaginable state. The participant's perception of their health continued to improve over 12months, from 56% at baseline to 83% at 12months.

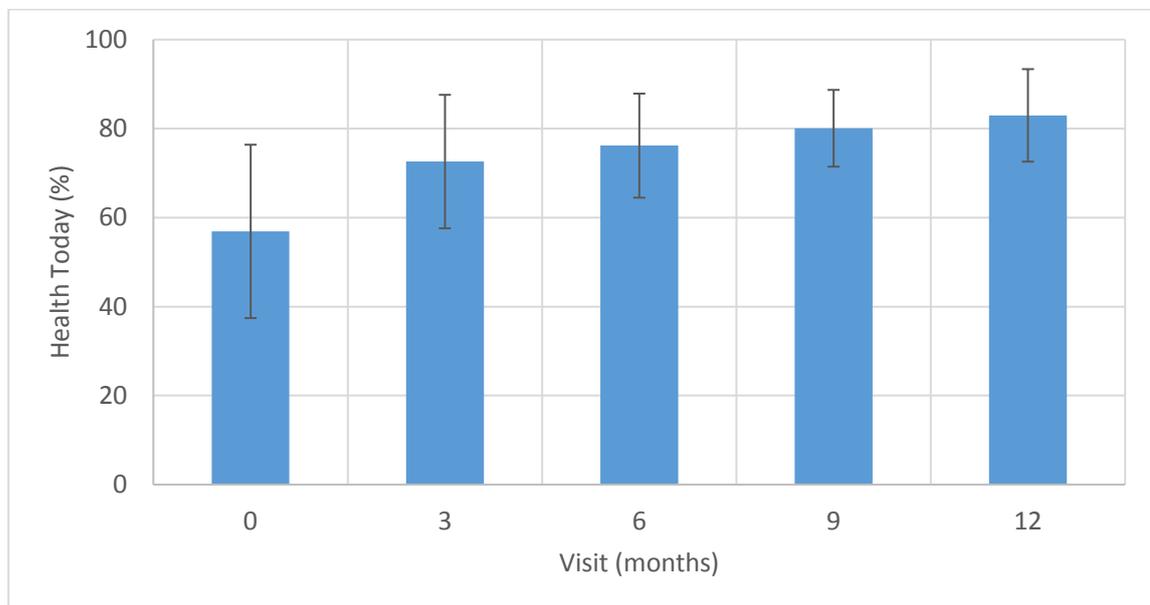


Figure 3.2.7 Participant responses regarding health state at baseline, 3, 6, 9 and 12months

The overall impact of the GAFG programme was evident. Participants made improvements but this clearly went broader than simply the volume of physical activity they completed. The positive impact of the programme was demonstrated in the way participants perceived their overall quality of life. Each of the areas discussed within this section had significantly improved which indicated the real difference the GAFG programme had made. What was interesting to note was that for the majority of factors investigated (4 out of 6) all positive responses peaked at 9months. Whilst there are possible explanations for the decline at 12months such as, the percentage of overall attendance decreased at 12 months therefore there were lower numbers, it appears that some consideration is warranted as to what may be happening at 9months. It is perhaps possible to suggest that 9months is a sufficient length of time to support participants in order to establish the necessary behaviour changes and a level of autonomy is achieved. Regardless of this, the positive impact of the GAFG programme was evident.

3.3. Qualities of the programme

The next section of this report discusses the data which emerged in relation to both participants and stakeholders perceptions of the qualities of the programme. As such, it addresses elements of two of the research aims, namely research aim 1: stakeholder's perceptions of the programme and culture change; research aim 2: perceptions of service provision amongst service users. There were several key themes that emerged from the data from both participants and stakeholders in relation to the qualities of the GAFG programme design and structure, these will be discussed together in the following sections. It is important to highlight that overall when interviewees discussed both the qualities of the programme and the benefits to participants that they felt this service offered something that was valuable and different to other forms of cancer or physical activity provision. As such, it was a positive addition to existing programmes of support.

3.4 Client-Centred Approach

The notion of uniqueness was reported by both participants and stakeholders in relation to the GAFG programme's *client-centred approach*. This was one of the most important and valuable elements of the GAFG programme, according to those interviewed. There were several aspects of the programme which interviewees felt encompassed this client-centred approach; *practitioners knowing the participant; practitioners knowing when and how to guide, motivate or give space; technology use; and bringing the programme home.*

3.4.1. Practitioners knowing the participant

When participants discussed their perceptions of the programme many expressed that they felt that the MPAP they were working with had taken the time to get to know them as an individual and that they understood them as people and on a personal level. As Participant G discusses during the phase 2 interview:

'Well I think (the MPAP) sat down with me at first, spent I don't know how long, longer than I thought and just sat down and talked about (pause) me as a person, physically but also me as a person, the treatment I'd had, erm how I feel physically, how I felt you know? And I think that's where she listened to what I had to say and then said right, OK...these are the steps that we will take, for you.'

This excerpt from the data highlights several aspects of the GAFG approach that participants valued. Firstly, the investment in time by the MPAP was important, this provided a space in which rapport could be built. Secondly and perhaps most notably, the approach used by the MPAPs enabled them to learn about the participant. The knowledge acquired here was not simply facts about the participants current health status or current physical activity levels but knowledge about that individual, their lives and cancer journey, in order to understand them *'as a person'*. It was this information which was perceived as valuable to the participants and stakeholders. This then acted as a thorough knowledge base for MPAPs to create support and a plan which was individually tailored or as participant G comments enabled the MPAP to identify *'the steps that we will take, for you'*.

Stakeholders also recognised this aspect of the programme and identified that it made this programme different to other forms of provision currently available. As discussed by a Clinical Nurse Specialist (CNS):

'I'll take my cue from them if they said I'd like to do a bit more or I'd like to get out and that's when you can talk about things like that again and I'll have somebody to support that and it's individualised care as well. You wouldn't get that if you went somewhere else you know? Unless you paid for that service.'

This investment in time and the approach taken by MPAPs within the first meeting is fundamental in the process of behaviour change. As Rollick et al. (2005) highlights it is important to establish the why and how of change early on when working with a participant. Acknowledging that this takes time, Rollick et al (2005) further suggest that skill consultation about behaviour change, including motivational interviewing is worthwhile and integral to the process of engaging individuals in the process of change.

3.4.2. A different type of support: practitioners know when to guide, motivate or give space

The knowledge gained through MPAPs taking time to get to know the participants also had an impact on the type and level of support subsequently provided to individuals within the GAFG programme. Both participants and stakeholders identified one of the key strengths of the programme was that *'practitioners know when to guide, motivate or give space'*. The type and amount of support discussed by each participant varied, for example, some referred to the goals which had been mutually set and monitored, others referred to the specific guidance and advice they had received from the MPAP. Similarly whilst some discussed the face to face contact, others discussed text messages or telephone calls from the MPAPs. This highlights further the value of individual and client-centred approach adopted within this particular programme. For example, Participant C who felt quite confident and able to participate in physical activity received support in the form of 'check ups' (texts or telephone calls) from the MPAP:

'I feel confident (pause) so they've given me something to do. I wouldn't (pause) do that off my own back. I wouldn't have gone and joined the gym but the fact that (the MPAP) checks up on me (pause) it's given me something to do and something to aim for you know? I wouldn't be able to do it on my own.'

In contrast, Participant H valued the face to face contact and the time spent with the MPAP as this motivated her, as an individual, to engage with physical activity:

'I want to get a bit more exercise and it's nice that you've got somebody you can talk to when you go for a walk, you know? I think she's (MPAP) really good at that. She's got, you know, like proper motivation skills.'

'She does, you know, text me and say right, what you doing, blah blah blah, or come over and we go training...and it's nice just to look forward to for her to come round and just, you know, we don't talk about cancer, you know, now she's my friend that she comes round...we'll just talk about this that and the other and go for a nice little long walk'.

Therefore the work of the MPAPs was flexible based on the participant's needs rather than a set system, process or timeline. This could not happen without the MPAPs really knowing each individual participant in the first instance.

Stakeholders also valued the variety of delivery and support provided within the GAFG programme. In particular the use of face to face contact was seen as being important when working with those with or recovering from cancer. As a Macmillan advisor and one CNS commented:

'People love one on one and I think particularly for patients who are palliative in nature he comes to their home, he sees them, he tailors something for them, something that purely to be life enhancing and quality of life, you know? Talking about the quality of people's lives I think people find that very helpful'.

'I think that with this kind of support even though these people do have a lot of other appointments to make, this appointment, that when they see these people (MPAPs) it is different it's, it's a much more approachable appointment and it's not something that they'd see as alongside all the other appointments that they have which are very medical and very clinical. Therefore I think it's, well it is crucial is that there is enough face to face contact and I think that was one of the areas that it's helps...and I think .. I think that still remains even though they're doing a remarkable job.'

In addition to highlighting the benefits of a face to face service, the Macmillan Advisor draws reference to the different nature of the GAFG programme. This was raised by other stakeholders too who commented positively about how this programme was different to other cancer services and also different to other physical activity services. Stakeholders also felt that this different approach was appropriate and necessary when working with participants with cancer or recovering from cancer. Stakeholders reported that this was an effective approach. When stakeholders discussed these differences they referred also to the components of a client-centred approach, namely face to face contact, individually tailored and providing motivation and guidance.

3.4.3. Technology use

Another component highlighted as an effective and a unique quality of the GAFG programme was the *use of technology*. Both participants and stakeholders felt that the use of digital technology through email, text and use of tablets for participant meetings was beneficial to both the process of referral and support throughout the programme. The benefits included being able to utilise a range of communication methods to support and best suit the individual participant. Different participants praised the use of different modes of

communication. Once again reflecting the perceived value of individual nature of the programme. As Participant G discusses about text support:

'It helps you from a psychological point of view, from the point of view that you know in a sense that people are there to help you but then also monitoring you...regularly...obviously it works on the individual as to how they feel you are you know?'

The use of technology enables the MPAPs to provide another layer of support and motivation in addition to the scheduled meetings with participants. This provided participants with a more continuous support system than otherwise would be available. In addition, it was noted that participants were encouraged to be active not passive in the participant-practitioner relationship:

'He basically checks up on me every three months and sees how I'm getting on and...he does send me texts saying 'how are you doing?' 'Are you OK?' 'You know you can always ring me' (Participant C).

Thus encouraging participants to take control of their own engagement with the programme by contacting the MPAPs if needed. Stakeholders also reported that the use of technology was a valuable component to GAFG. This was in relation to both the referral process and the support and motivation provided to participants. As the quotes below from a CNS and Macmillan Advisor demonstrate:

'I think that it's very easy to refer to because what we do, is do it via the secure net account like email, so I, you know, I've offered that as well to Doctors because obviously there is a referral form but that, you know, a lot of people don't want to fill a form in do they? But they don't have to and you know they can do it that way'.

'(When discussing the use of tablets and video blogs) I've not seen that done before in any other programmes that I've been linked in with. It tends to stay in people's memories that and as I say with it being new it it's (pause) well it certainly had the impact on me anyway'.

3.4.4. Bringing the programme home

One of the key success factors of the GAFG programme highlighted from the data was that participants did not have to travel in order to access the programme, in contrast the programme was *brought into the home*. Not only was this considered by interviewees to be unique but was essential to the success of this particular programme. It improved the reach of the service and ability to access participants who did not feel able to access a programme otherwise. Some participants, like Participant H, were left feeling low in confidence after their cancer and cancer treatment. Participant H discussed how she lacked the confidence to leave the house or socialise with others. Therefore it would have been difficult for Participant H to access a service like GAFG unless the service came to her. Participant H organised her phase 2 away from her home, which in itself indicates a change in confidence. During the interview she discussed how the programme had impacted on her confidence and everyday life:

'It's made me a lot more confident I used to be nervous like just coming here on my own, I used to feel really embarrassed walking in here (garden centre) on my own whereas now I just get on with it no bones about it. Erm I'll now quite easily just go sit in the corner and wait for my friend to turn up or go shopping round the town on my own. You know there's a couple of girls on the street who like really intimidate me and they were out in the street I'd wait till they'd go in the house before I went out. Now I just go out and yeah its boost me up so much'.

The value of being able to provide a service at home for those with cancer was recognised by both participants and stakeholders. Furthermore it was evident that the use of technology and paperless nature of the programme enabled this. As reflected upon by one MPAP and one CNS:

'Right down to things like giving a paperless service to us doing the travelling so the person didn't have to come to us ...and we're finding that a lot of other programmes require you to travel to them so they might be embedded in a leisure centre which doesn't necessarily you know draw someone to want to go there'.

'I think because it's at home...and it will probably give them that bit of confidence and they know they're seeing somebody who's going to always come to them you know, they come and they take your history and talk through everything with you so it's not just you know right come on we'll go on ten mile hike'.

In relation to how stakeholders perceived the programme and had changed provision for cancer, it is evident that from those interviewed that the service was highly valued and in many cases had become embedded in existing provision. All of these qualities of the service were identified as being not only different to other services but highly relevant to the needs of those who were experiencing or had experienced cancer. These qualities also combine to create an effective client-centred approach to providing physical activity support to those with or recovering from cancer. This is important as, when individuals are fully engaged in the process of change (through the techniques used by the MPAPs) the more likely they are to maintain that change and for it to become habitual (Rollnick et al, 2005).

3.5 Timing

In addition to the data which highlighted the qualities of the programmes, two key themes emerged which related to the timing of the programme, namely that the *time of access or referral* was key and that the programme was *filling a void* in current provision.

For participants on the programme many identified that for them, the GAFG programme had been introduced to them at the right time. For some, GAFG had come at the right time because they were ready to try and 'get back to normal' or get back to life before cancer. For others they were ready to try and improve their lives post cancer. As Participant G reflected back during her third phase interview at 12months:

'(The MPAP) still keeps in touch with me which is nice and she still comes and see me but...they helped me at a critical period when I needed the help at the time'.

Similarly Participant C comments on how important it was for him to be introduced to the GAFG programme at the right time:

'I needed help you know building my strength up...and that's how it's gone from there you see. I think I think she's (MPAP) made me think positively about erm, actually getting off my backside and doing something. As I say it's so easy to fall into the trap where you're not doing things. It's very easily done...it's a very easy trap to fall into this cancer business'.

Therefore participants identified themselves that the timing of referral had been right for them. It is important to note (as outlined in section 3.1) the majority of participants were referred when their cancer was stable. That is not to say that this is the right time for all referrals to take place but the participants interviewed within this research reported it was the right time for them. In addition, the CNS' play a pivotal role in the referral process for many of those engaged in the GAFG programme and as such act as a gatekeeper, offering or recommending the service when they think it is appropriate to the participant. As discussed by one CNS:

'Well wouldn't say that I've referred an awful lot no erm, and that's probably largely because most of the people that drop in are erm, newly diagnosed. On that basis (pause) they wouldn't really be appropriate referrals because somebody has just been diagnosed although I might say to them something along the lines of you know erm try and maintain activity and keep yourself healthy I also feel that at that time they probably got enough on their plate you know... with referral appointments and diagnostic tests and that sort of thing ... but the ones that I have done are, have been a little bit further down the road where people are maybe coming to the end of treatment or just finished treatment'.

As outlined in section 3.2 (see figures 3.2.1, 3.2.2 and 3.2.5), some data suggested that the benefits of the programme peaked at 9 months. It is interesting to note that some participants also identified during their phase 3 interviews (9-12months) that they now felt they were had reached a point of independence and could control and manage their physical activity themselves. Participants commented that they 'knew their bodies now' and 'had established a routine'. Indeed, in one case a participant felt that they had outgrown the programme.

'With Macmillan, probably I've made my life now. I'm only saying that because don't get me wrong I don't think there's anything else they can do for me' (Participant G, Phase 3).

It is important to acknowledge that this is the perceptions of a small number of participants. However, when this is taken alongside the quantitative data it adds further to the need to examine what type of support and provision is wanted but also required from 9 months onwards to ensure that participants' continue to engage in physical activity.

The final theme relating to the timing of the GAFG programme relates to how the programme fits within existing cancer and physical activity provision and as such it is evident that the programme is perceived as *filling a void*. Previous sections of this report have highlighted that both participants and stakeholders consider many aspects of the programme to be unique and highly appropriate to the needs of those with cancer. Alongside this, data from participants highlighted that GAFG filled a void which existed between cancer support and mainstream physical activity provision.

'When I finished my treatment (pause) the Macmillan nurse at the oncology department at Lincoln hospital said to me, said now obviously we're not going to be seeing you for about three months but is there anything you feel we can do? And this is where Fiona came in. I do feel I need to build my strength up I said (pause) I feel so weak. She said leave it with me...and the next thing Fiona phones...so that was the connection'.

Stakeholders also felt that the GAFG programme was filling a void in current provision, as discussed by CNS':

'After treatment a lot of our patients get really lost afterwards. They feel a little bit (pause) shall we say abandoned because the cancer sort of erm, path way shall we call it, can be so intensive and sometimes so long that that at the end of it, you know they get told that OK, you're sort of better you know, off you go... something like this gives them a real focus, to sort of improving and maintaining good health'.

'I think the key strength is that we're actually targeting people with a specific need which is great rather than just bunching them in together...we're looking at specific needs and specific requirements for these people at different stages of their journey through cancer....and I think that's

key. Rather than just being referred by their GP on to specific programmes. I do think that they need someone (pause) to help them through this'.

Therefore the GAFG programme was providing an aspect of support which was previously absent from cancer and physical activity provision and was in the viewpoint of both participants and stakeholders, an invaluable programme which meets the specific needs of those with cancer or recovering from cancer.

3.6. Perceived barriers to further expansion of the programme

Whilst stakeholders thought the service was unique, appropriate and relevant to those with or recovering from cancer, the data highlighted two potential barriers to the programme in relation to its continuation and expansion. These were *the time intensive nature of the client-centred approach* and the existence of *pockets of referral*.

Despite acknowledging the value and need for a client-centred approach, similarly to the data from the interim report, stakeholders continued to express some concern over how viable it would be to utilise this approach with the same levels of staffing, should the programme expand, either in relation to the number of participants or geographically. As discussed by one CNS:

'It's a specialist service you know you'd be overwhelmed if you (pause) if we did every single patient and, and it wouldn't be appropriate. I would say if you had a lot of referrals coming through about how many staff you have to do this? Because you know...we've really got a small amount of people so it's hard to deliver that with the staff because I understand you only have got two.'

As can be seen from the data in section 3.1, it is evident that participants are recruited from several key geographical areas. This has become more diverse since data was collected for the interim report at

12months and therefore it is evident that the programme has increased its reach in the last 12 months. Despite this, it is clear that recruitment over the first 24 months of the programme tended to come from some key areas, suggesting some *pockets of referral*. This is likely to be a symptom of geographical challenges faced when working in a largely rural county. The challenge is likely to have impacted on the ability of MPAPs to market and promote the programme over a vast county. The researchers are aware that the MPAPs have undertaken some extensive marketing prior to the publication of this report. If this marketing is successful then there should be an increase in the reach of referrals over the next 12 months. If this is to be the case then it would be appropriate to consider ways in which the programme would ensure that the client-centred approach would not be compromised due to increased demands and expansion of the programme, as a result of an increased number of participants to visit and subsequent need to travel.

3.7 Participants experiences of cancer and physical activity

The next section aims to outline the key findings which emerged from the analysis of the qualitative interviews with participants who were engaged in the GAFG programme. The findings from this data revealed there were three key themes and a series of sub-themes which related to the participants embodied experiences and perceptions of the programme (Research Aim 3). Sections 3.7.1 to 3.7.3 are concerned with data where participants discussed their perceptions of cancer, their cancer journey and sense of self. It provides an understanding not only of how participants reflect upon how their cancer impacted upon themselves and their identity but also how the participants perceived and valued the GAFG programme in relation to their cancer and physical activity. Most significantly, it provides an understanding of how the GAFG programme influenced how the participants perceived and managed their cancer.

3.7.1 Identity

When analysing the data it was evident that, for many, their cancer journey had led to feelings of loss, most notably, a perceived loss of their *identity*. The participants interviewed reported experiencing a perceived threat to their identity as a result of cancer diagnosis and/or treatment. This was frequently embodied through a change in their appearance and physical capability which was out of their control. This threat to identity according to Frank (1995) is a process of narrative reconstruction whereby the 'ill self' is incorporated as part of the individual's personal story, in this case, the participant's cancer journey (Frank, 1995; Mathieson & Stam, 1995; Reynolds, 2002; Whitehead, 2006). When analysing data from participants, narrative types were used to display the significance of the findings, these types relate to life-limiting illnesses as proposed by Frank (1995). Frank (1995) identifies restitution (identity retained), quest (identity transformed) and chaos (identity lost). These narrative types are not exclusive and it is acknowledged that these narratives change over time in response to both intrinsic and extrinsic factors, one such factor was being engaged with the GAFG programme.

3.7.2. Restitution - 'Getting back to 'normal'

The most common narrative typology displayed by participants in relation to their identity was *restitution*. For many participants, It appeared to be most important for the participants to 'get back' to what they perceived to be 'normal', namely their pre-cancer state. Therefore participants who articulated *restitution* narratives were striving for their pre-cancer identity. Participant F even gave this its own specific term, describing their desire to return to life 'B.C.' (Before Cancer). The below statements from phase one interviews serves as examples of participant's *restitution* narratives:

'I think it's because of the breast reduction. If I'd just not had that operation (pause) just had the cancer removed I think it would have been (pause) but I mean I want to get that out of the way as soon as possible really, coz I am feeling really odd like this (pause) waiting to get back on track again

really. I just feel odd at the moment whereas when I get the other breast reduced then I'll feel more normal again .So I really want to get in and get it out of the way ASAP then I think then I might feel (pause) a little more normal' (Participant C).

'I had an element missing and there was a power missing (pause) I was lost and weak (pause) I needed to get back and I couldn't (pause) felt like I was out of control. I don't want to blow my trumpet but I come from a family that's very strong, physically strong, I was (pause) but the strength is coming back, it is coming back. I'm getting back to normal' (Participant H).

Here Participant C & H discuss how important it is for them to get back to their pre-cancer self, or 'B.C.' self. Participants in the GAFG programme utilising this *restitution* narrative viewed their cancer as a temporary state and looked forward to a time when health would be restored (Frank, 1995; Nanton et al, 2016). Many of the participants during interviews conducted at 0-3 months described their feelings about cancer (whether their diagnosis, treatment or recovery) as a period of *restitution*.

How participants conceptualised their identity (either before, during or after cancer) was multi-faceted and varied from individual to individual and it is important to acknowledge this. There were however some common themes which arose when participants discussed cancer and their identity. Many participants discussed their identity in relation to the loss of the physical self through a reduction of strength, mobility or changes in body image which was often discussed by participants in relation to weight gain or loss. As discussed by Participant C during two of the interviews:

'Because of all the tablets I was on and I couldn't do a lot because I couldn't walk a lot so I put on a lot of weight' (Participant C Phase 1).

'I was always worried about putting weight on as I was just sitting round the house and not wanting to go out...and then not being able to wear the clothes you want to buy' (Participant C Phase 3).

In addition to discussing their identity in relation to the physical self, many discussed the ways in which cancer had effected their psychological and social self also. In particular participants referred to loss of confidence, mental strength and ability and desire to socialise.

In all of these cases, for those articulating *restitution* narratives, the GAFG programme enabled them to 'get back' to their pre-cancer identity. The programme provided a focussed opportunity for participants to help rebuild themselves and achieve their previous identity. For many, this was the most important outcome of the GAFG programme. Therefore many participants described what they felt they had lost and then discussed how the GAFG programme had helped them 'get back'. As discussed by the following participants:

'Oh, my main achievements really are doing as I've said you know, building up on the exercise regime, building up the walking and generally just being more active. In other words, initially I was tired and weak I used to spend quite a lot of time just sitting in a chair but now I try to sit down as little as possible...all I want to do is to try to get back to how I was before' (Participant F, Phase 2).

'It (GAFG) has made me a lot more confident...I used to be nervous, like even being here on my own...I used to feel really embarrassed walking in here on my own...whereas now I just get on with it...it's boost me up so much' (Participant H, phase 2).

The design of the GAFG programme with its emphasis on motivational interviewing and client-centred behaviour change enabled participants to reflect and identify in their own mind both; which aspects of their identity or self, have been lost through their cancer journey and what aspects still remain; and what aspects of their identity they wished to regain and how physical activity would feature as part of this.

3.7.3 Quest - 'Looking forward and being a 'better' me'

Whilst some participants felt that the GAFG programme was enabling them to 'get back' to their pre-cancer identity and feel normal, others were '*looking forward*'. These participants viewed the GAFG programme as an opportunity to better themselves and enhance their identity as a result of realisations, changes in their motivation and feelings of hope that by transforming or improving themselves illness may not strike again (Bourke et al, 2015). This idea of transformation in illness, according to Frank (1995), is termed a *quest* narrative. Within this research, some participants articulated *quest* narratives, these individuals saw their cancer diagnosis as a moment of realisation and now want to better their identity. As Participant F discusses:

'Before cancer I think I was a bit of a couch potato... I didn't do anything but I never really did any exercise at all. It's a shame that I've waited until I got cancer and something dramatic that made me realise that I should be exercising and look after myself more ... I do think that it would have been good if I'd have kind of discovered that before I'd got the cancer ... but at least I can do what I can do now and live a more active lifestyle, more than before' (Participant F).

Participant F's aim is to better her life and increase her activity as she did not engage in physical activity prior to diagnosis, thus making a positive lifestyle change and in turn improving her identity. Participants articulating their experience through *quest* narratives tend to show attributes of the disciplined body as they feel they are in control (or want to take control) of their lives and more importantly their bodies. Furthermore they consider their bodies as a tool to be worked on in order to better themselves compared against their

pre-cancer self. From the initial phase through to the final phase, participants displaying *quest* narratives continued with the same attitude towards physical activity and its ability to change their lifestyle and identity throughout the three phases. These participants used the physical activity experienced as part of the GAFG programme to build upon and enhance their identity and reach their end goal of being a better version of themselves prior to their cancer journey. Data suggests that the self-loss was initially a critical construct in their adaptation to cancer and their identity processes influenced their vision for the future. The participants did not want to only become themselves again, they wanted to improve and make lifestyle changes to achieve this (Golub, Gamarel and Rendina, 2014).

Similarly to those with restitution narratives, for those individuals with quest narratives the GAFG programme design and approach enabled them to reflect upon the changes they wished to make to their lives, through engaging in motivational interviews and client-centred discussions. Subsequently, a programme of support and goals could be mutually agreed to meet that individual's needs. It is important to note that whilst this data suggests that participants demonstrated one of three narrative types, the use of these narratives by individuals changed over time, resulting in a highly individualised cancer journey. The approaches used within the GAFG programme allows the MPAPs to respond to the individual's cancer journey and changing narrative. Therefore, strengthening the need for programmes like the GAFG programme to take an individualised client-centred approach.

3.7.4 'Coping with Chaos'

In contrast to the participants who demonstrated *quest* narratives a few of the participants displayed *chaos* narrative qualities when referring to their loss of identity, whereby the impact of cancer had taken over their lives and were struggling to take back control and strive to improve their health. The below quote is an example of a *chaos* narrative:

'I'm frail now compared to a year ago. I have noticed quite a lot quite a difference. I'm not me, not able to do anything completely at all sometimes. But I mean you do get different people who react in different ways (pause) but I can't do anything about it (pause) I felt that (pause) it was pointless doing that, it is not going to help (pause) I've got cancer it's not going to take it away. There's no miracle cure' (Participant I).

Participant I's cancer had continued to progress since being diagnosed and due to no improvements being made, they felt a degree of lost hope or identity therefore leading to feelings of loss of control and being overwhelmed (Nanton et al., 2016). Participants can create a possibility of maintaining a connection through some strategy or contextual resource, with elements related to a pre-illness identity. The GAFG programme is such a resource, with participants like Participant I using physical activity to aid the process of rebuilding themselves and reaching their ultimate goal of being back to their pre-cancer state, if not better (Nanton et al., 2016).

The data within this demonstrates that participants from each of the three narrative types were engaging and benefitting from the GAFG programme but in different ways. For participants demonstrating restitution narratives who were aiming to get back 'normal' or their 'B.C.' self the GAFG programme enabled them with an opportunity to recapture their physical, social and mental identity. For some this was specifically about their physique, body weight and body image.

'Well at first I physically I could not have done those (activities) but now I feel that I've built up, feel my arms...I mean I was very thin with little muscles but now... they're all coming back you know.

Overall I'm physically stronger and that's the big thing about it... then I was so incredibly weak, so incredibly tired and the tiredness bit has gone ...That's all gone.' (Participant C).

For others this related more broadly to the way the programme enabled them to access activities and interaction they perceived as 'normal' or not cancer related. Participant's demonstrating *quest* narratives experienced moments of realisation, hope and motivation and a desire to move forward from cancer. The GAFG programme provided them with an opportunity to improve their life to make it better than it was before cancer, to get fitter, healthier and better manage themselves, life and their bodies. As Participant H and Participant C comment:

'(The programme) made me realise, making me think a lot differently about my lifestyle for a start. I mean didn't hardly exercise before I was over majorly overweight, ate loads of rubbish, processed food. Since I met Fiona I started slimming and lost nearly a stone already' (Phase 1).

'I think without Macmillan I'd probably sat in a chair, weighing heavier, not being able to get up. I think just by going on their programme and being with them, that at least allows me to do things myself, do the house work' (Phase 1).

Finally, for those participants articulating *chaos* narratives, who still felt they were struggling to control or cope with cancer, the GAFG programme still acted as a resource by which these individuals could begin to cope and rebuild their identity at some stage.

3.8. Outcomes of the programme

Section 3.2 demonstrates that the programme was impacting on participants by improving their physical activity levels and quality of life. Section 3.7 reported that participants felt that their engagement with the programme had enabled them to recapture their identity and in some cases improve their identity by improving fitness, health and managing their weight. In addition to this, the interviewees also articulate that participants felt the service had enabled them to regain *control, independence* and improve their *confidence*. Therefore the sections that follow discuss this and further address research aim 3.

3.8.1 Empowered to take control and be independent

In addition to participants reporting feeling a loss of identity through their cancer journey, many participants referred to feeling out of control. In relation to the GAFG programme, both participants and stakeholders identified that the programme enabled participants to regain control. Data showed that participant's control status changed from interviews conducted during phase one of the programme to phase three. In order to display this, quotes from phase one and phase three will be used to demonstrate the way physical activity enabled participants to regain *control*.

'I always did sports; I played football, darts... I went to the gym... I couldn't have been more active... now I wouldn't be able to do any of those... it's not like it was even my choice... I physically can't now because of everything I've had in my body... the treatment has shot me down and I'm having to attempt to rebuild back to what I was... everything gets taken from you in an instant and you can't do anything to stop it... You've just got to keep fighting and get back in control' (Participant B, Phase 1).

'It's been such a long journey, but I've felt myself progressing throughout since doing more activity... I feel more myself now, like I'm back in control again... back to me almost... obviously there's still areas to be worked on and I'll keep going till I'm back to 100%... I have neuropathy in my hands and feet which is another obstacle but I won't let it stop me... it's like everything got taken away from me but I've been clawing it back since I've been getting fitter and stronger' (Participant B, Phase 3).

There are a number of ways in which the programme and physical activity enabled participants to feel they were regaining control. Firstly, engaging in physical activity was discussed by participants and stakeholders as being an experience which is the antithesis to their experiences of cancer. Living with cancer and cancer treatment can make the individual feel like their body and lives are now under control of the illness and the people who work to try and help (Nanton et al, 2016). In this sense, individuals experience body dissociation, where individuals become disassociated and passive from their bodies. In contrast physical activity encourages body association, where individuals see their bodies as their own and are connected. When participating in physical activity, the individual controls how much activity they engage in, can stop when they like, move as much or as little as they like. Consequently, the process of being physically active is an empowering one. Within phase three interviews, the individual displayed genuine dedication to physical activity which made them feel in control of their bodies, over their new situation and abilities. In order to move forward with their life, there was a need to “re” store, or “re” establish a sense of balance where the participants' changed physical self was integrated into their personal life and a coherent future visualised (Bourke et al, 2015). The sense of control gained through physical activity also manifested itself in other aspects of the participant's lives. As discussed by Participant H:

'I found this programme and it's what I needed... pointed me in the right direction... at first I was completely lost and had no idea what to do... I was left with nothing physically... the most important thing to me physically... was my strength... it's something I've always been proud of and I was stripped

from it... I made the aim to beat it and beat it so good I was better than before' (Participant H, Phase 1).

'After everything I've been through (pause) it made me want to stand up and take control of my life. I've always wanted to run my own business and I finally got the courage to quit my job and do it (pause) I was fed up of being treated like crap, I was constantly getting physically stronger and it meant I could do what I used to but for me not someone above me (pause) I built things for people who took profit now I build them for people but I'm the boss (pause) I feel empowered (pause) I'm in a better position I've ever been' (Participant H, Phase 3).

Therefore for many participants they were able to not only regain control of their bodies through engagement in physical activity but also transfer this into other aspects of their lives. This transfer from control in a physical domain to other areas of life enabled them to increase their *independence*.

Despite the act of engaging in physical activity being important within this process of regaining control, the process, techniques and tools used by MPAPs (as discussed in section 3.3) were integral to enabling participants to gain control and become more independent. As a CNS highlights this when discussing the difference in approach to treatment and the GAFG programme:

'(In treatment) you have to do what other people tell you all the time. (In the GAFG programme) I think that's really important...it's going to somebody's house as well so they're in control... it's all about control and there's no pressure they (participants) have got that control'.

The programme was seen as being different to others which individuals with cancer would access throughout their journey:

'it's the fact that we're going in and we're you know ... and you know we're not going with that very kind of black and white approach of we're not here to talk about medicines or treatment. That's what your CNS (Clinical Nurse Specialists) will cover you know and all those questions should be directed at those professionals. We're here to look at your health and lifestyle well-being, what you can do for yourself and what we can help you with' (MPAP).

The final sentence within this quote emphasises both the participant taking control '*what you can do for yourself*' and the support which empowers the participant to do so '*what we can help you with*'. It is evident from the data analysed that these two aspects of the client-centred approach, which is unique and different to other services, were those which led to participants feeling able to take control of their physical activity and thus feel more independent.

3.8.3 Confidence

Finally, when participants made reference to gaining or regaining their identity, control or independence it was often coupled with a reference to feeling more confident. In a sense, participants gained confidence which in turn led to them feeling more like their "B.C." self or feeling more able to regain the control or independence they lost through cancer. Therefore confidence is key to this process. For example Participant C discusses how the GAFG programme has made them feel confident to take control of their lives:

'It's made me, I won't do anything that I don't have to do any more (pause) my outlook on life completely changed...as in, if I don't want to do anything (pause) I won't really do it and if I really want to do something I'll make sure I can do it'.

The development of confidence was also related to the realistic goals set by the MPAPs and the individually tailored programmes. Participants were set achievable goals which once they had achieved led to an increase in confidence. Once again this was an integral element of the client-centred approach of the GAFG programme.

4.0. Evaluation Summary

This report provides a detailed analysis of data collected and analysed over a two year period in order:

1. To assess reach, efficiency and impact of services amongst providers and partner organisations, and to ascertain the degree of potential culture change within these organisations, including perceptions of the value of the programme.
2. To assess perceptions of service provision amongst service users with cancer in the county of Lincolnshire over an 18 month period and to assess service uptake, adherence and attrition through this period.
3. To assess participant perceptions of the guidance received, together with reflections on their embodied experiences of physical activity during their engagement with the programme.

A detailed summary of the key data emerging from this research is provided in section 1. There are some points to conclude when considering the implications of this data for the future of the GAFG programme or for providers of similar programmes in other areas. Firstly data suggests that the programme design and structure, utilising behaviour change and motivational interviews, was highly regarded by both participants of the programme and key stakeholders. In addition, this approach was considered to be both unique and appropriate to working with those living or recovering from cancer. Whilst this was highly valued, stakeholders did highlight that this approach was time and labour intensive and felt further staffing would be needed if the programme was to expand.

Secondly from stakeholders and participants interviewed, it was evident that the programme had filled a void in existing provision and it had become a valued part of the services available to those living or recovering from cancer. The programme bridged the gap between cancer support and mainstream physical activity provision. Data highlighted that the majority of referrals occurred when participants' cancer was

stable. It would be worthwhile reflecting upon this pattern and consider whether the programme team wishes to develop the potential to work with those at other stages of their cancer journey.

Thirdly, data from this research highlighted that the programme had a positive impact on programme participants. In addition to improvements in physical activity levels the programme led to participants: improving their quality of life, regaining their pre cancer identity, regaining confidence and increased feelings of control and independence. Quantitative data suggested that for a number of measures, the impact of the programme peaked at 9months. It appears that some consideration is warranted as to what is happening at this time point and whether a change in the type or volume of support post 9months is needed.

5.0 References

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