

# Cognitive Rehabilitation and Support Project – Evaluation Report

## Transforming Care after Treatment

Final version

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## **ACKNOWLEDGEMENTS**

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The statistics in this report are the results of a self-evaluation carried out by local project staff with support from Edinburgh Napier University TCAT Evaluation Team. The views expressed in this report do not necessarily represent those of Edinburgh Napier University or Macmillan Cancer Support.

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## **EXECUTIVE SUMMARY**

### **Background**

The burden of cancer and its treatment can have lasting physical, psychosocial and economic consequences for survivors and their families. Cognitive dysfunction associated with cancer and its treatment is an issue of survivorship which can present significant challenges for individuals due to cognitive functions being critical to many complex behaviours of daily life. Many referrals to the Beatson Clinical Health Psychology Service pertain to issues around cognitive dysfunction following cancer treatment. Securing two years of funds under Phase 2 of the Transforming Care after Treatment (TCAT) programme presented a valuable opportunity to test a new model of care for supporting individuals with cognitive changes post treatment.

### **Methodology**

The project aimed to raise awareness, knowledge and skills/confidence in health and social care staff, third sector colleagues and employers in the identification and support of patients who are experiencing cancer-related cognitive changes through the provision of teaching/training and relevant self-help materials. For those patients experiencing significant degrees of impairment, a pilot group cognitive rehabilitation intervention designed to address difficulties related to cognitive dysfunction following cancer treatment was offered. The cognitive rehabilitation intervention consisted of five group sessions and was delivered between April 2016 and September 2017 in community settings to optimise access. Individual sessions were also offered for individuals unable to access the intervention in a group format. Patient reported outcome measures were collected prior to and on completion of the intervention. The standardised measures assessed participants' psychological functioning (PHQ-9; GAD-7) and distress of cognitive changes on quality of life (FACT-Cog).

With regards to the development of staff training and self-help resources pertaining to cancer-related cognitive changes (CRCC), a staff survey and patient focus group were carried out to inform its content. The survey conducted in April/May 2016 aimed to ascertain baseline levels of staff awareness of CRCC and their confidence in supporting their patients with this aspect of post treatment care. Individuals who had attended the cognitive rehabilitation group programmes within the first six months of the project were invited to participate in a focus group aimed at ascertaining their views on information they would have liked to have received from their medical teams; terminology which best encapsulates the cognitive difficulties they experience; and clarifying what is helpful to know about CRCC. The project steering sub-group (self-help materials) took on the responsibility of overseeing the development and implementation of the staff training and acted in an advisory capacity to the project clinician.

### **Results**

One hundred and eighty-three referrals were received in total, of which 66% (n = 121) accepted a cognitive rehabilitation intervention, either in a group or individual format. The vast majority of individuals (83%) referred to the project accepted a group-based cognitive rehabilitation intervention (n = 100) whereas only 17% (n = 21) chose an individual intervention. The 91% retention rate for the group intervention suggests that this type of

support delivered in a group format is an acceptable mode of intervention delivery for this patient population. Individuals with breast (40%) and haematological (20%) cancers were most commonly referred to the project. This may be indicative of existing support structures, such as the breast follow up clinic at Stobhill Hospital and the Haematology late effects clinic. Based on research estimates, individuals with other cancer diagnoses are likely to present with CRCC and could benefit from specific support with these concerns, therefore the referral rate for these tumour groups does not necessarily reflect the potential need.

Ninety-four completed quality of life and psychological functioning outcome measures were collected from individuals who completed the programme, either for individual or group sessions. Outcome data indicates that group participants' distress reduced significantly post intervention. On average, participants remained within the moderately severe range of depression following the group programme, whereas participants' levels of anxiety reduced from moderately severe to the moderate range following the group programme. Qualitative data suggests that the information provided on how cancer and cancer treatments can adversely impact cognitive functioning, alongside practical strategies of adapting to cognitive changes within a group context can facilitate effective adjustment with this issue of survivorship.

Staff training in CRCC was delivered by means of the project conference entitled: *"Memory and concentration changes after cancer treatment. What do we know? What can help?"* which was financially supported by Macmillan Cancer Support. A patient booklet on cancer-related cognitive changes was produced and circulated to clinical teams; Third Sector; Local Authority (primarily the Improving Cancer Journey team); and Primary Care for use in their roles in supporting individuals with this issue of survivorship. Three short educational videos on CRCC aimed at patients and their families were produced by NHS Greater Glasgow and Clyde Medical Illustration department which featured two service users speaking about their experiences of living with and adapting to cognitive changes secondary to their cancer treatment.

## **Conclusion**

The project was successful in achieving what it set out to do in relation to its three primary aims i.e. to deliver cognitive rehabilitation support; to develop supplementary CRCC resources and to liaise with a variety of health and social care professionals across care settings in developing their capacity to support individuals with this aspect of survivorship. Within the broader context of the national TCAT programme, the project aimed to initiate and embed an integrated and sustainable approach to support provision specific to CRCC in collaboration with health, social care and third sector partners. It is envisaged that the CRCC information resources and the training sessions in the cognitive rehabilitation approach aimed at Clinical/ Counselling Psychologists and specialist Occupational Therapists working in the third sector and NHS will serve to develop capacity amongst a diverse group of professionals to deliver a stepped model of care and respond to the cognitive support needs of cancer survivors. The willingness and renewed confidence witnessed amongst staff groups to contribute to this aspect of care, coupled with cancer survivors' demands for integrated care of their whole wellbeing will be the ultimate drivers for change.

## SECTION 1 – INTRODUCTION

### 1.1 Introduction

Within the past decade, there have been strategic levers in health and social care that have driven forward transformational change in rehabilitation service delivery, alongside improvements in patient care. In Scotland, *Better Cancer Care: An Action Plan* (2008) and *Beating Cancer: Ambition and Action* (2016) have set out the significant shifts that are necessary to improve the wellbeing of cancer survivors. The recent cancer strategy identified gaps in service provision and called for a joined-up approach between health and social care, as well as third sector services, in order to develop sustainable and innovative approaches to cancer care. In line with improved survival rates, a renewed emphasis is required on enhancing follow-up services to support the ongoing health and wellbeing needs of the individual. The strategy operationalised this ambition in terms of enabling people living with, and after cancer treatment to have access to information, advice and support tailored to their individual needs.

The inception of the Transforming Care after Treatment (TCAT) programme therefore aims to address this aspect of service provision. The TCAT programme is funded by Macmillan Cancer Support and delivered in partnership with people affected by cancer, Scottish Government, Regional Cancer Networks, NHS Boards, Local Authorities and the Voluntary Sector. A total of 25 TCAT projects across Scotland have been tasked with developing and testing new models of care, with a particular emphasis on individuals being empowered to engage in supported self management following cancer treatment. The focus on self management approaches however also recognises that unlike the management of many other chronic diseases, cancer treatments can have unique and potentially serious short-term and long-term consequences. The adoption of follow-up that is person-centred and risk stratified, incorporating holistic needs assessments and individual care plans can go some way in ensuring that this support is tailored to the individual needs.

The burden of cancer and its treatment can have lasting physical, psychosocial and economic consequences for survivors and their families. One of the key concerns highlighted by individuals relates to coping with the emotional effects of a cancer diagnosis and adjusting post treatment. In 45% of cases, the emotional legacy of active cancer treatment is cited as being more difficult to cope with than the physical and practical effects of cancer (Macmillan, 2006). Cognitive dysfunction associated with cancer and its treatment is just one area among a broad range of survivorship challenges. Nonetheless, memory and attention problems secondary to cancer treatment can present significant challenges for patients in survivorship due to cognitive functions being critical to many complex behaviours of daily life. For example, planning, goal setting, word finding and task organisation which are necessary for effective functioning at home and the workplace depend on robust cognitive performance. Moreover, within the national context of cancer care, cognitive changes rank eighth amongst the ten most frequently reported concerns after treatment (Edinburgh Napier University, 2016).

## 1.2 Cognitive dysfunction secondary to cancer treatment

A substantial body of evidence indicates that a significant proportion of cancer survivors experience ongoing cognitive dysfunction following cancer treatment (Ahles et al., 2012; McDougall et al., 2014). A number of meta-analyses have concluded that research findings consistently demonstrate the adverse impact of cognitive function associated with chemotherapy and radiotherapy (Jansen et al., 2015; Anderson-Hanley et al., 2003; Matsuda et al., 2005), with evidence that cognitive difficulties can occur independently of mood state (Brezden et al., 2000).

Cognitive difficulties have been described across various cancer types, including breast cancer (Falletti et al., 2005), head-and-neck cancer (Gan et al., 2011), brain tumours (Gehring et al., 2010) and haematological malignancies (Schulz-Kindermann et al., 2007). Difficulties have been particularly associated with high intensity anti-cancer treatments (Gehring et al., 2012). Cognitive difficulties specifically following brain tumour treatment have been reported (Costello et al., 2004; Gehring et al., 2010).

Although some individuals report improvement in their cognitive functioning during their recovery, there is evidence that these difficulties can persist over the long-term for some people (Fardell et al., 2011; Ahles et al., 2012; McDougall et al., 2014; Jansen et al., 2005; Anderson-Hanley et al., 2003; Matsuda et al., 2005). For instance, De Ruiter and colleagues (2011) reported a relatively stable pattern of cognitive impairment 10 years after chemotherapy in a breast cancer population.

Cognitive dysfunction associated with cancer treatment can manifest in a range of cognitive deficits including difficulties with memory, attention, concentration and executive functioning (i.e. planning, organisation and problem solving). The mechanisms of these difficulties are thought to be related to side-effects of treatments, including high dose chemotherapy, intracranial radiotherapy, hormonal treatments, bio-immunotherapy, adjunctive medications or the cancer itself prior to treatment. Research has shown that there are often differences between objective and subjective reports of cognitive changes, suggesting that psychological factors such as depression, anxiety and fatigue are likely to also impact on the perceived level of deficit. Cancer-related cognitive impairment (CRCI), cancer-related cognitive changes (CRCC), or 'chemo brain' are terms also used to describe changes to thinking processes after cancer treatment.

Estimates of the prevalence of cognitive dysfunction varies depending on a number of factors, including cancer type and stage, treatment type/dose, as well as methodological issues. A recent literature review concluded that cancer-related cognitive impairment is highly prevalent, remaining present in up to 35% of patients many years following completion of treatment (Janelsins et al., 2014). Specific to breast cancer, a meta-analysis (Matsuda et al., 2005) found that chemotherapy-induced mild cognitive impairment occurred in 10-40% of breast cancer patients, with memory loss and lack of concentration the most frequent symptoms. This is in line with other recent research (Ganz et al., 2013)



which reported that, following adjuvant treatment, around one in five breast cancer patients had increased cognitive difficulties.

### **1.3 Impact of cognitive dysfunction on quality of life**

In a review of qualitative research examining survivors' experience of cancer-related cognitive impairment (Myers, 2013), self-reported experiences were found to be consistent across tumour types and gender. The desire to be informed about the potential for cognitive changes was commonly expressed, along with the need for recognition, assessment, and validation by the health care team. Cognitive changes were described as having a significant impact on quality of life, self-confidence, and independence. Patients noted the wide-ranging impact of cognitive difficulties, affecting home life and relationships as well as employment.

Cancer survivors have identified that the validation of their cognitive concerns and the development of specific coping strategies are essential to adjustment (Von Ah et al., 2013). Janelsins and colleagues' review (2014) notes that there is currently limited research on interventions for cancer-related cognitive impairment, but preliminary findings on strategies designed to maintain function were described as promising. Similarly, other research teams have recognised both the limited quantity of research focussing on interventions to date, as well as the potential benefit offered by cognitive behavioural interventions (Fardell et al., 2011; Von Ah et al., 2013).

Cognitive changes may not be identified or recognised by health or social care professionals or by employers. Specific training and awareness-raising of the types of difficulties patients can experience following cancer treatment and how these are best managed is therefore essential in ensuring that people are optimally supported in their return to work and/or maximising their independence.

### **1.4 Cognitive rehabilitation interventions – evidence base**

A small number of published studies have outlined cognitive rehabilitation interventions with some promising results. Ferguson et al. (2012) reported on their randomized clinical trial (RCT) of Cognitive Behaviour Therapy (CBT) for chemotherapy-related cognitive change, with positive patient outcomes. These included significant improvement on measures of quality of life and verbal memory performance and high patient satisfaction. Schuurs and Green (2013) describe a group cognitive rehabilitation treatment which they found to be helpful in reducing participants' perceptions of cognitive impairment and psychosocial distress, as well as promoting social functioning and understanding of cognition. Gains were maintained three months post-intervention and participants again reported a high level of satisfaction with the intervention. They concluded that the study lent support for the feasibility of a brief group-based cognitive rehabilitation intervention to address cognitive problems experienced by cancer survivors. McDougall et al. (2011) similarly reported positive outcomes from their memory training intervention which incorporated aspects of cognitive behavioural therapy. Cherrier and colleagues (2013) reported on a seven-week cognitive rehabilitation group intervention which included content on memory aids,

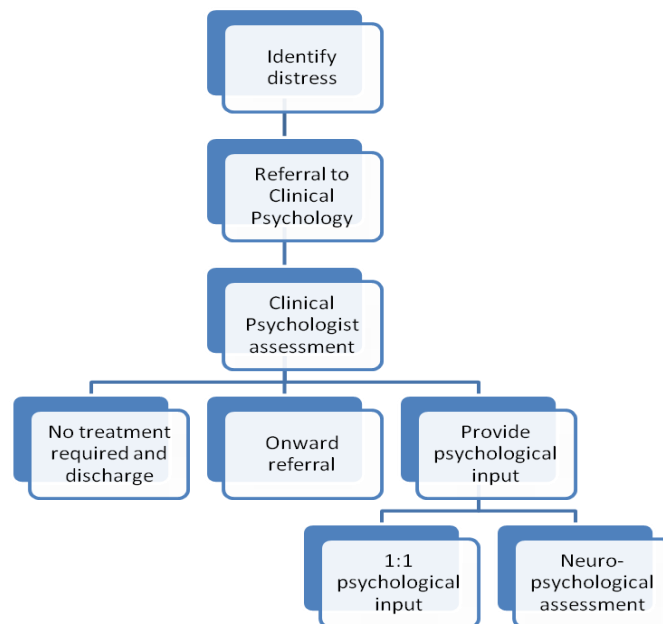
development of memory skills and mindfulness. The intervention was found to be effective in improving attention abilities and cognitive-related quality of life.

Gehring et al. (2009) conducted a randomized controlled trial of cognitive rehabilitation for patients with gliomas, reporting a beneficial effect on short-term cognitive complaints and longer-term cognitive performance and mental fatigue. Locke et al.'s (2008) study found that patients with brain tumours who have cognitive impairment can participate meaningfully in a structured cognitive rehabilitation intervention incorporating compensatory strategies, which was well-received by participants. Hassler et al.'s (2010) pilot study concluded that group-based neuro-cognitive training is feasible for patients with high-grade gliomas and may help improve attention and memory skills.

In summary, research suggests that, on average, around 35% of patients who have been treated for cancer will experience cancer-related cognitive changes (CRCC). Such difficulties can have a negative impact on various domains including activities of daily living, quality of life, return to work and relationships. The awareness and assessment of these difficulties could be enhanced through training of staff in health and social care sectors and with employers. The majority of patients will experience mild-moderate degrees of impairment and therefore do not require specialist neuropsychological input and could be optimally managed through the provision of self-help and structured guidance. Existing research highlights the need to address cognitive dysfunction following cancer treatment. Group interventions using a cognitive behavioural approach show promise, but the need for further work in this area is widely recognised. This project will therefore constitute an additional evidence-based resource to enhance the support offered to patients experiencing treatment related cognitive dysfunction.

### **1.5 Transforming Care after Treatment (TCAT): Cognitive Rehabilitation and Support Following Cancer Treatment Project**

The Clinical Health Psychology Service in the Beatson West of Scotland Cancer Centre (BWoSCC) provides an assessment and treatment service for patients with significant psychological problems in relation to their diagnosis and/or treatment. On average 8000-8500 new patients attend the Beatson West of Scotland Cancer Centre per year, therefore given the research estimates that around 35% of patients who have received cancer treatments will experience some degree of CRCC, it could be concluded that up to 2800 patients per year treated at the BWoSCC are likely to present with cancer-related cognitive problems. As illustrated in the figure (1) below, individuals referred to the Clinical Health Psychology Service are supported with their broader psychological needs, including managing cognitive changes as part of their overall psychological adjustment throughout all stages of their treatment and recovery.



However, many referrals to the service pertain to issues around cognitive dysfunction following cancer treatment and therefore a dedicated resource may help offset the anxiety expressed by patients and caregivers in relation to the lack of information or available interventions to help manage and adapt to these difficulties. Securing two years of funds under Phase 2 of the Transforming Care after Treatment (TCAT) programme presented a valuable opportunity to test a new model of care for supporting individuals with cognitive changes post treatment. It was anticipated that a new model of care would entail the following aspects:

- patients being asked about their cognitive functioning as part of their follow-up care e.g. as part of their holistic needs assessment (HNA);
- patients being provided with written and audio-visual information about cancer-related cognitive changes and signposted to further support, if appropriate;
- patients being offered an assessment of their cognitive functioning, and if appropriate, offered a cognitive rehabilitation intervention to support their needs.

## 1.6 Aim and Objectives

### Aim:

- Provide additional specialist, tailored psychosocial interventions to support patients and their carers who are experiencing cognitive impairment secondary to their cancer or its treatment.

### Objectives:

- Provide training to health, social care, 3<sup>rd</sup> sector colleagues and employers/Occupational Health departments to raise awareness of these difficulties

and give guidance on the management of such issues. Key partners in this would be the Improving Cancer Journey Team and the Macmillan Learning and Development Managers.

- Compile information booklets/resources for use in community, acute and primary care settings, outlining specific cognitive rehabilitation strategies relevant to cancer related cognitive changes (CRCC). This could link in closely with Macmillan's "Back to Work" toolkit.
- Deliver a 6-week group-based intervention for patients presenting with more complex/severe CRCC and their carers to provide psycho-education regarding the nature of cognitive dysfunction secondary to cancer treatments and support them in the implementation of evidence-based cognitive compensatory strategies. This could be delivered in both Hospital and Community- Based settings, e.g. GP practices, to ensure optimal access. Limited access to individual support will be available for those patients for whom a group is not suitable or appropriate.
- Refer/signpost to other community/health resources for support with related issues which may be identified.
- Share progress and learning locally and nationally to enable spread of resources.

## **SECTION 2 – METHODOLOGY**

### **2.1 Project design**

The project aimed to raise awareness, knowledge and skills/confidence in health and social care staff, third sector colleagues and employers in the identification and support of patients who are experiencing cancer-related cognitive changes through the provision of teaching/training and relevant self-help materials. For those patients experiencing significant degrees of impairment, a pilot group cognitive rehabilitation intervention designed to address difficulties related to cognitive dysfunction following cancer treatment was offered.

A triaging process was developed, whereby those patients who had been identified/assessed as having mild cognitive deficits post-treatment were directed to lower intensity support via self-help information and guidance. This was achieved through the use of existing supports and structures e.g. the holistic needs assessments performed by the Improving Cancer Journey team, Occupational Health assessments, Welfare Rights Officers, and follow-up appointments with medical/nursing staff. Patients assessed as having more complex problems were directed to the cognitive rehabilitation group.

This section will outline how these three components of the project; the cognitive rehabilitation intervention, staff training and self-help resources were developed, implemented and evaluated.

### **2.2 Clinical governance**

The project lead Dr Chris Hewitt, Consultant Clinical Psychologist established the implementation and steering group to oversee the development, implementation and evaluation of the project. The terms of reference were agreed at the first meeting on 20<sup>th</sup> April 2015. This group was made up of representatives from a range of key stakeholders, as outlined in Appendix I (steering group membership).

The role of this local project steering group was to:

- Introduce the assessment of cancer related cognitive changes (CRCC);
- Raise awareness, knowledge and skills/confidence in health and social care staff, 3rd sector colleagues and employers in the identification and support of patients who are experiencing CRCC;
- Through education seek to address cognitive rehabilitation and support following cancer treatment with the provision of teaching/training and relevant self-help materials;
- Involve appropriate stakeholders (secondary / primary / social care / third sector) ensuring wide discussion and agreement on the process, and support ongoing implementation;

- Utilise already established communication processes to inform service teams of work that is underway, and where appropriate devise alternative method of communication;
- Agree timescales for delivery local group objectives;
- Establish a process for robust evaluation; and
- Ensure mechanism in place to 'share and spread' the successful outcomes of the tested new approaches.

In support of this local steering group six operational sub-groups were established following the first meeting with a view to ensuring delivery of the project plan. The diagram (Appendix II) illustrates the reporting structures which supported this programme of work.

### **2.3 Project staffing**

Dr Natalie Rooney was recruited in February 2016 as the 0.6 wte Clinical Psychologist fulfilling the role of project manager with the responsibility of the day to day running of the project and ensuring targets were reached and outcomes were achieved. Louise Bryan was recruited in May 2016 as the project administrative assistant whose role was to organise and administer the delivery of self-help materials and group/individual interventions and overall administration of the project.

The administrative assistant left her post in December 2016 which prompted a review of the administration requirements of the project. It was decided that the recruitment of an Assistant Psychologist would be an asset to the project. An Assistant Psychologist is a psychology graduate with experience of working in clinical settings and therefore could assist with the development of CRCC self-help resources, co-facilitate the group intervention, as well as assist with the overall administration of the project. The project manager met with the Regional TCAT Clinical Lead and the TCAT Programme Manager in December 2016 and agreed that given that an existing member of the Clinical Health Psychology department could fill this role and therefore avoiding gaps in service delivery an (0.4 wte) Assistant Psychologist could be recruited to replace the administrative assistant. Victoria Grant, an experienced Assistant Psychologist with previous work experience of neuro-psychological presentations from the Institute of Neurological Sciences, Queen Elizabeth University Hospital, worked on the TCAT project between January 2017 until September 2017.

### **2.4 User involvement**

Following consultation with Simon Malzer, TCAT User Involvement Manager, members from the TCAT programme Cancer Experience Panel (CEP) were invited to represent the panel on the steering group. Diana Johnston volunteered for this role and remained the link CEP representative throughout the duration of the project. In addition, Breast Cancer Care nominated a representative and Catriona Gorton joined the steering group in 2016. The patient representatives contributed significantly to the development and evaluation of the project, in particular with the self-help materials component.

From the outset, the clinical psychologist strove to fully embed the service user voice throughout all stages of the project and to this end attended training in the co-production approach on 20<sup>th</sup> June 2016 at the Macmillan offices, Glasgow which was provided by Olivia Hanley from the Scottish Community Development Centre. The training aimed to increase understanding of co-production; explore opportunities to apply a co-productive approach; and provide an opportunity to ascertain how co-production principles could be incorporated within current practise. The project clinician regularly consulted with the TCAT programme user involvement manager about how best to incorporate co-productive principles within the development, implementation and evaluation of the project. Further discussions were held with the Phase 1 Stobhill breast project to glean insights on how they developed a service user panel to inform their project.

## 2.5 Development Phase

As illustrated in the timeline below, the development phase of the project entailed the following:

- Development of referral pathways, patient information and referrers' leaflets;
- Design of the cognitive rehabilitation intervention;
- Raising awareness of the cognitive rehabilitation service;
- Design of CRCC staff training and self-help materials.

## Development Phase



## 2.5:1 Development of referral pathway

Appendix III includes copies of the referral pathway, referral form, patient and referrers' leaflets which were developed in collaboration with the Steering Group assessment sub-group.

Based on a review of the literature, coupled with discussions with neuropsychology colleagues, a self report cognitive screen was indicated for ease of use and being sensitive to subtle cognitive changes. Research indicates that a brief screening measure such as the Montreal Objective Cognitive Assessment (MOCA) or the Mini Mental State Examination (MMSE) is used to rule out more severe impairment, coupled with a self report measure on quality of life (Wefel et al., 2011). The International Cognition and Cancer Task Force (ICCTF) recommends using the FACT-Cog, a quality of life measure developed by the Functional Assessment of Chronic Illness Therapy (FACIT - [www.facit.org](http://www.facit.org)) to assess the impact of cognition on cognitive functioning in cancer patients. The Clinical Psychologist registered the project with FACIT to access scoring and interpretation materials for the subjective cognitive screen (FACT-Cog).

An initial assessment for the cognitive intervention therefore entailed (please refer to Appendix IV for copies of outcome measures):

- Objective cognitive screen – Montreal Cognitive Assessment (MoCA)
- Subjective cognitive screen – FACT-Cog
- Psychological functioning - GAD-7; PHQ-9
- Clinical interview to ascertain the extent of cognitive difficulties and screen for any significant cognitive deficits or psychological distress that may impede their ability to participate in a group intervention. Onward referral if appropriate e.g. Older Adults community mental health team for memory clinic assessment.

Given the variety of potential referrers to the programme across the acute, community, third sector and local authority settings, the steering group requested that assessment and referral protocols were aligned with clinical competencies of the respective referrers. For example, it was discussed that the Improving Cancer Journey (ICJ) team would use a similar protocol to that currently used for triaging/making referrals to the clinical psychology service i.e. when a patient highlights from Concerns Checklist or in discussion with holistic needs assessment officer that they were experiencing cognitive problems, the FACT-Cog quality of life assessment tool would be administered. If patients scored in the lower range, they would be directed to self-help materials/resources. If in moderate – severe range, they would be given information regarding the project and, if in agreement, a referral would be made. To this end, the clinical psychologist conducted a training session on 22<sup>nd</sup> April 2016 for the ICJ team regarding the referral process, including an overview of cancer-related cognitive changes and cognitive rehabilitation.

In order to reduce the burden from clinicians in referring to the project, it was agreed that referrals could be made directly to the service and the clinical psychologist would screen and triage accordingly. Referrals from Third Sector organisations entailed providing



information on the cognitive rehabilitation to patient groups, and self referrals were facilitated.

### **2.5:2 Design of the cognitive rehabilitation intervention**

Based on the psycho-oncology literature as delineated in the introductory section, as well as advice provided by Dr Nicola Goudie from the Community Treatment Centre for Brain Injury (CTCBI) a five-week group intervention was designed with the following content:

- Week 1:** How does cancer treatment affect my memory?
- Week 2:** Attention – What is it? How can I improve it?
- Week 3:** Memory – What is it? How can I improve it?
- Week 4:** Planning and Problem Solving – What is it? How can I improve it?
- Week 5:** Tying it all together! Summarising the information and coping strategies covered in the course. Open to family member/ friend to raise awareness of these common memory difficulties.

The intervention aimed to provide group participants with information about the impact of cancer and cancer treatments on their cognitive functioning coupled with cognitive compensatory strategies to help understand, adjust to and ameliorate the effects of cancer treatments.

In addition, the project clinical psychologist attended the British Psychological Society (BPS) training event “*Chemobrain: what do we know? What can we do?*” in March 2016 as a means of ascertaining current approaches being utilised to support patients with cognitive concerns. This event featured expert speakers on CRCC including: Professor Robert Ferguson (University of Maine, US); Dr Daniela Montaldi (University of Manchester); Dr Oana Linder (University of Leeds); and Medical Oncologist Dr Kirsty Balachandran. A specialist interest group for cognitive rehabilitation in psycho-oncology services was established following this event which provided opportunities for the project clinician to consult with cognitive rehabilitation experts in the design of the group intervention.

### **2.5:3 Raising awareness of the cognitive rehabilitation intervention**

As the development of the group and individual cognitive rehabilitation interventions was a new initiative within the Beatson Clinical Health Psychology Service, concerted effort was made to raise awareness of this resource amongst health and social care professionals, as well as local authority colleagues within acute and community settings. The service was launched on the 15<sup>th</sup> April 2016 at the Beatson Education session and follow up presentations were delivered with a range of clinical staff. For example, the project clinician met with groups of Clinical Nurse Specialists (CNSs) across specialities in both NHS Greater Glasgow and Clyde and NHS Ayrshire and Arran to promote the new service. Liaising with services represented on the steering group was a key priority in the initial stages of the project, namely Primary Care, Cancer Support Scotland (Calman Centre), Macmillan (Glasgow Council Libraries Project), Maggie’s, Specialist Health and Work Service (The Beatson Cancer Charity) and Breast Cancer Care which entailed meeting with staff to raise awareness of the new service. A consistent theme arising from these consultations with

staff highlighted a gap in knowledge about CRCC and lack of information resources to support patients presenting with this condition.

In addition, links were made with other TCAT projects to incorporate the provision of cognitive rehabilitation within existing cancer pathways, namely:

- Holistic Needs Assessment (HNA)
- End of Treatment Summaries (ETS)
- Health and wellbeing events
- Cancer Care Reviews in Primary Care

It was anticipated that the use of an HNA would facilitate the identification of specific cancer-related memory and concentration difficulties. The collaboration with the Improving Cancer Journey (ICJ) team and clinical teams employing HNA assessments was therefore an integral part of this project. The project clinician closely liaised with the TCAT projects employing both the HNAs and cancer care reviews namely; Phase 1 Stobhill breast cancer, Phase 2 NHS Lanarkshire lung cancer, Phase 2 NHS Lanarkshire cancer care reviews and Phase 2 Renfrewshire Health and Social Care Partnership projects in order to raise awareness of the service.

#### **2.5:4 Design of CRCC staff training and self-help materials**

Alongside the delivery of the cognitive rehabilitation interventions, an additional aim was to raise awareness, knowledge and skills/confidence in health and social care staff, 3<sup>rd</sup> sector colleagues, and employers in the identification and support of patients who are experiencing CRCC through the provision of teaching/ training of relevant self-help materials.

In order to ascertain baseline levels of staff awareness of CRCC and their confidence in supporting their patients with this aspect of post treatment care, a survey was designed in collaboration with the subgroup of the steering group overseeing the evaluation of the project. The online survey was distributed to a range of health and social care professionals, and local authority colleagues in April/ May 2016. Please refer to Appendix V for a copy of the staff survey.

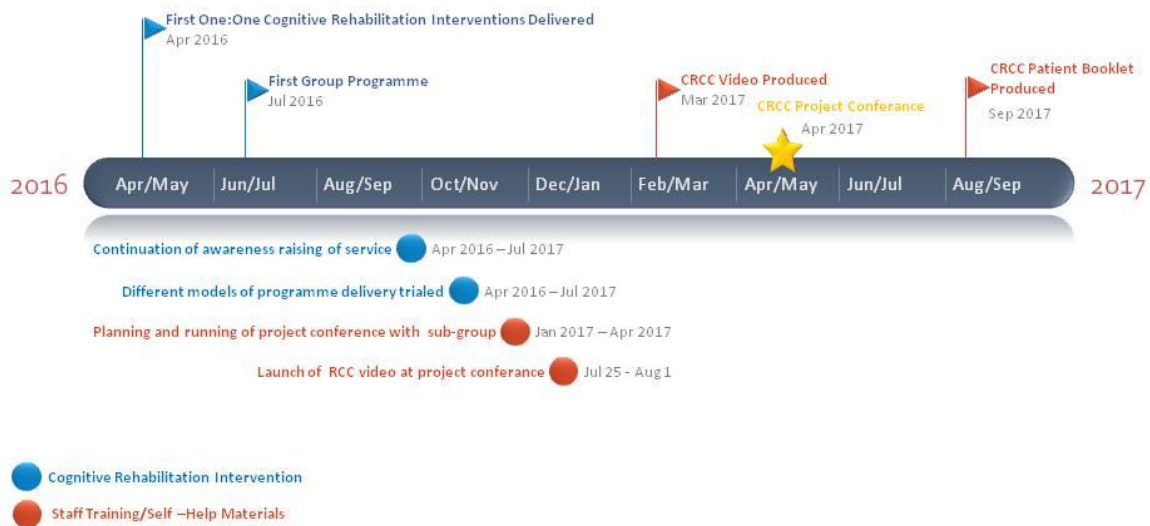
As a means of seeking service user feedback to incorporate within the development of the self-help materials, a focus group was held on 24<sup>th</sup> October 2016 at the Mitchell Library, Glasgow which was facilitated by the steering group's two patient representatives Catriona Gorton and Diana Johnston alongside the project clinician. Simon Malzer, TCAT Service User Involvement Manager and Vicki Cloney, Beatson Cancer Charity volunteer/ Oncology Nurse were also in attendance in observing roles. Individuals who had attended the cognitive rehabilitation group programmes were invited to participate in a focus group aimed at ascertaining their views on information they would have liked to have been told by their medical teams; terminology that best encapsulates the cognitive difficulties they experience; and clarifying what is helpful to know about CRCC.

Data obtained from both the staff survey and the patient focus group were used to inform the development of the training and self help materials components of the project. The self-help materials sub-group consisted of Madaline Alexander, Operations Manager, Cancer Support Scotland; Lorraine Crothers, Specialist Occupational Therapist, Community Treatment Centre for Brain Injury (CTCBI); Catriona Gorton, Diana Johnstone, patient representatives. This sub-group also took on the responsibility of overseeing the development and implementation of the staff training and acted in an advisory capacity to the project clinician. The subgroup met twice and corresponded regularly by email.

The subgroup reviewed the existing CRCC information resources and proposed to revise the existing information leaflets to incorporate the cognitive coping strategies which were demonstrated in the group intervention, thereby providing a stand-alone resource for clinicians. In terms of producing educational videos on CRCC, the subgroup advised to explore the option of approaching graduates of the cognitive rehabilitation programme to ascertain if they would be willing to be filmed speaking about their experiences of living with and adapting to cognitive changes post treatment and to liaise with NHS Greater Glasgow and Clyde's Medical Illustration department in the production of these videos. The project clinical psychologist and assistant psychologist took on the tasks of writing the scripts for the introduction and coping strategies videos.

## 2.6 Implementation Phase

# Implementation Phase



As outlined in the timeline above, the cognitive rehabilitation intervention was delivered between April 2016 and September 2017. The intervention consisted of five weekly two-hour sessions facilitated initially by the project clinical psychologist only, and from January 2017, co-facilitated by both the project's clinical psychologist and assistant psychologist. Initially MS Powerpoint slides were used as a visual aid. However, based on clinical observations, coupled with patient and carer feedback, from January 2017 flipchart and A1 posters were used as an alternative visual aid in order to increase accessibility.

The groups were held in local authority and NHS community settings including:

- Glasgow City Council Libraries;
- Eastbank Health Promotion Centre, Shettleston;
- New Victoria ACH;
- Gleniffer Outreach Centre (Accord Hospice), Royal Alexandria Hospital;
- Wishaw Health Centre, Lanarkshire.

Due to an increase in referrals received from Lanarkshire, the project clinician offered individual assessment appointments for individuals living within this catchment area by accessing one of the GP surgeries. A couple of individuals had raised limited access to transport as being a barrier to attending the group programmes. The project clinician therefore secured accommodation at the Wishaw Health Centre to deliver a one-off course

for Lanarkshire based individuals and met with the TCAT Phase 2 NHS Lanarkshire cancer care reviews operational group to promote the group programme and encourage referrals from the practice nurses.

Throughout the implementation stage of the project, different models of delivery were trialled such as providing an evening group option; opening up the last session of the programme to caregivers, as well as providing a separate group for individuals with brain tumours. In the initial stages of the project, separate group interventions were delivered for individuals with a Central Nervous System (CNS) tumour e.g. glioma in order to provide an opportunity for participants to discuss the additional impact that this condition can have on cognitive functioning. However, the low referral rate for this specific group of individuals, coupled with the wide geographical spread which included East Dunbartonshire; West Dunbartonshire; North Lanarkshire and Glasgow city, impacted adversely on attendance thereby resulting in a separate intervention for CNS tumours not being viable. Moreover, it was observed that as a group of individuals, they were well informed about the cognitive aspects of living with a brain tumour. They reported receiving good support from their medical team, particularly in relation to understanding the impact of their tumour on daily functioning. Additionally, a few participants reported gaining significant benefit from the support of the Brain Tumour Charity; Brainstrust and Maggie's Glasgow. Following discussion at the steering group in January 2017, it was agreed that individuals with a CNS tumour diagnosis subsequently referred to the service would be offered the opportunity to attend the general group cognitive rehabilitation programmes.

An evening group option was also offered. However, there was no uptake to this course. A few individuals who had initially raised conflicting work commitments as a barrier to attending had arranged leave in order to attend the day groups and there was a lack of response from the remainder of individuals. The evening group option was deemed as not meeting the needs of individuals and therefore not offered as a routine part of service delivery.

## **2.7 Evaluation/ Dissemination Phase**

The evaluation process aimed to establish whether the programme improved patient care, outcomes and experience and met the needs of users. The effectiveness of the intervention was assessed by:

- Patient feedback/evaluation of self-help materials.
- Feasibility of group cognitive rehabilitation intervention (engagement, retention, attendance rate).
- Acceptability / patient satisfaction of group intervention (Questionnaire &/or qualitative interview/focus groups).
- Subjective impact of cognitive functioning on quality of life. Assessed using the Functional and Cognitive Assessment of Cancer Therapy – Cognitive Function Version 3. (FACT-Cog).
- Anxiety – assessed using General Anxiety Disorder. Version 7 (GAD-7)
- Mood – assessed using Patient Health Questionnaire, Module 9 (PHQ-9)
- Functional impact – assessed by qualitative feedback from participants

Outcome data collection started in April 2016 and carried through until September 2017 which was collected prior to and completing the group programme.

## Evaluation / Dissemination Phase



### 2.7:1 Dissemination of cognitive rehabilitation training and information resources

As illustrated in the timeline above, training of staff and dissemination of self-help materials was conducted between October 2017 and January 2018. By raising awareness of the new resources and learning which had been developed by the project, it was envisaged that clinicians would be equipped with the required knowledge and resources to support individuals with cognitive issues at tiers one and two and when to triage to more specialist services. A three-pronged approach was adopted to achieve this aim.

#### 1. Train the trainer

Prior to the evaluation stage of the project, consultations were held at steering group level to ensure that mechanisms were put into place for the transfer of learning with regards to the delivery of the cognitive rehabilitation interventions. The outcome of consultations between the TCAT clinical lead and the project clinicians proposed that the sustainability of the interventions and information resources could be facilitated in a similar way to the National Education Scotland (NES) Developing Practice training. The NES Train the Trainer

model is organised around initial training in the *Developing Practice* course, followed up by twice yearly trainers' events where materials are discussed and general support discussed. NES also holds central data from all training courses which have been delivered so that a national audit and database of outcome data is maintained. A similar model could be used with the cognitive rehabilitation training programme and resources developed from the project to facilitate ongoing governance and monitoring/ evaluation. Initial discussions were held with the NES Clinical Psychology in Physical Health leads in January 2018 regarding the feasibility of overseeing the training in cognitive rehabilitation.

In April 2017, the project lead was approached by the psychology lead for Scotland Maggie's Centres, Dr Lesley Howells, Consultant Clinical Psychologist to discuss the possibility of rolling out the cognitive rehabilitation programme throughout their centres. This presented an opportunity for the cognitive rehabilitation intervention to also be delivered in non-acute oncology settings across various Scottish regions. In November 2017, the project lead and clinical psychologist met with the TCAT programme manager and clinical lead to discuss sustainability plans, specifically for the potential roll-out of the cognitive rehabilitation intervention Scotland-wide. These discussions highlighted the potential for ongoing collaboration between the psychologists employed within the various Maggie's Centres and specialist oncology clinical psychologists and Occupational Therapists (OTs) with a rehabilitation background.

A training event was therefore arranged for 18<sup>th</sup> January 2018 aimed at Clinical and Counselling Psychologists and specialist OTs to present the findings of the project; train the attendees in delivery of the intervention and to initiate discussions relating to the feasibility and service needs pertaining to future project delivery, with a view to establishing equitable service provision across Scotland. The event was attended by eleven clinicians with a specialist interest in cancer rehabilitation. The attendees represented are outlined below:

- Maggie's Centres (Lanarkshire; Forth Valley; Fife; Dundee; Highland)
- NHS Psycho-oncology/Clinical Health Psychology services (Lanarkshire; Forth Valley)
- Occupational Therapists (Neuro-rehabilitation services, Queen Elizabeth University Hospital, NHS GGC; Marie Curie and Strathcarron Hospices)

Dr Howells advised that the Counselling/ Clinical Psychologists from the Glasgow, Edinburgh and Aberdeen Maggie's centres were keen to collaborate with this initiative however they were unable to attend on the day. Dr Howells anticipates that the learning and materials would be shared through clinical supervision meetings with the remaining Maggie's centre psychologists. The initial plan following this day was that both Maggie's Centre psychologists and NHS psycho-oncologists and oncology OTs might collaborate in the future planning of the delivery of the intervention, acknowledging that the format of delivery will need to be flexible, depending on clinical demand and service design. This would ensure that most health boards would potentially be able to offer this intervention and that clinical governance and quality of training are assured. These discussions are ongoing.

## **2. Self management**

As part of a stepped care model for supporting patients with CRCC concerns, self management training can enable health and social care professionals to utilise the self help materials with limited clinical follow up, akin to approaches adopted for brain injury patients.

On 14<sup>th</sup> December 2017, a training event was offered to third sector/voluntary organisations to raise their awareness of the resources which are available to support self-management of patients with cognitive difficulties, to feel confident in directing patients to these resources and discuss the basic underlying principles of these approaches. The training was well received and attended by a range of third sector organisations and representatives from Clinical Nurse Specialist teams:

- Macmillan Cancer Support helpline;
- Breast Cancer Care;
- Specialist Health and Work Service (Beatson Cancer Charity);
- Practise Nurse (representing GP practises delivering the cancer care reviews);
- Haemato-oncology CNSs

Additionally, the project clinical psychologist liaised with Clinical Nurse Specialist groups across the West of Scotland region to share the CRCC information resources with a view to promoting the information resources and how these can be helpful for their roles in supporting patients. Similarly, resources were shared with the Macmillan Support and Information Managers at their quarterly meeting on 13<sup>th</sup> June 2017 and the ICJ team on 1<sup>st</sup> February 2018.

A particular emphasis of the project was to establish how its outcomes could contribute to some of the existing programmes of work within Macmillan. The project clinical psychologist liaised with the Macmillan work programme team to discuss how the resources developed from the project, as well as lessons learned, could potentially be incorporated within their programmes of work. The self-help materials (paper and audio-visual) have been forwarded to the specialist team with a view to them being potentially incorporated within Macmillan's existing suite of information resources, in particular the *Back to Work* toolkit. This is subject to review.

## **3. Collaboration with Professor Robert Ferguson regarding the Memory and Attention Adaptation Training (MAAT) programme**

Further to Professor Ferguson's input to the project conference in April 2017, he offered to facilitate a training workshop in order to deliver his Memory and Attention Adaptation Training (MAAT) programme for clinicians based at the Beatson West of Scotland Cancer Centre (BWoSCC). He is currently collaborating with cancer centres in the US and Canada as well as Warwick University in the UK. Professor Ferguson is keen for clinicians at the BWoSCC to become involved. The commitment entails delivering the MAAT intervention



(either 8 face-to-face sessions; or 4 group sessions) with patients, with the patient completing a questionnaire online prior to and after the intervention. The target for all research sites is 50 assessments, thereby an expectation of 10 assessments for the Beatson. Collaboration with Professor Ferguson's research was deemed by the steering group as being conducive to sustainability pertaining to several aspects of the project.

The MAAT training workshop was held on 11<sup>th</sup> January 2018 at the BWoSCC which was attended by four Clinical Psychologists, two rehabilitation specialist Occupational Therapists and one service user who has contributed to the training aspects of the project. The MAAT clinician manual and survivor workbook were distributed to all participants with a view that these will serve as useful resources for the delivery of the intervention.

### **2.7:2 Sharing the learning**

The learning from the project has been shared through oral and poster presentations at various conferences attended by a range of health and social care professionals. The assistant psychologist presented an overview and evaluation of the group intervention at the NHS Scotland conference which was held on the 20<sup>th</sup> – 21<sup>st</sup> June 2017. (refer to Appendix VI) The poster abstract was one of 234 selected out of a total 494 submissions and the conference scientific committee provided feedback as follows:

*“great to see co-ordinated, multi-faceted intervention, clearly addressing identified need. – great to see person centred focus and cross sector approach to facilitating self management.”*

*“A well written and compiled abstract with clear descriptions of why the project was needed, the methods used to bring about improvements and outcomes.”*

The clinical psychologist and project lead (Dr Chris Hewitt) presented an overview of the project at the WoSCAN Haemato-oncology MCN education event on 25<sup>th</sup> January 2017. The clinical psychologist delivered a presentation in collaboration with two service users who had accessed the group intervention which entailed an overview of the project's findings and cancer-related cognitive changes to social care professionals at Macmillan's Social Care Professionals conference in May 2017. In November 2017, the clinical psychologist co-presented with two service users at the Beatson Brain Bootcamp about the project and its impact on follow up care for individuals with a CNS tumour.

Additionally articles summarising the project's initial findings were published in the following newsletters:

- MacVoice;
- Leukaemia Care;
- NHS Greater Glasgow and Clyde Employment and Health Team, Healthy Working Lives newsletter to employers – estimated reach of 978 contacts and approximately 200 organisations;
- NHS Greater Glasgow and Clyde SNAPSHOT (Clinical Psychologists working in NHS GG&C).

The information resources and session materials for the cognitive rehabilitation group were shared with Clinical Health Psychology colleagues in Cardiac Rehabilitation and Stroke Rehabilitation with a view to delivering specialist cognitive support for their patient groups. Cardiac Rehabilitation Clinical Psychologists have since rolled out 'Memory Matters' group programme for their patient group, thereby highlighting the transferability of the project materials for supporting individuals with multiple long-term conditions. In response to the MacVoice article, the clinical lead for Occupational Therapy at Guy's and St Thomas' NHS Foundation Trust contacted the project clinician and information resources/session materials were shared accordingly.

The work of the project and its contribution to the development of person-centred support services was recognised in the Scottish Health Awards 2017, whereby the clinical psychologist was selected as finalist in the therapist category.

## **SECTION 3 – RESULTS**

This mixed methods project evaluation used various sources of quantitative and qualitative information including:

- Demographic data on service users (n = 183)
- Retention and attrition rates of the cognitive rehabilitation intervention (n=121)
- Outcome data on services users who attended either a group or individual cognitive rehabilitation intervention (n = 121)
- Feedback from service users gathered from
  - A focus group (n = 9)
  - Individual accounts (n=4)
- Feedback from staff needs analysis survey (n = 50)
- Feedback from conference delegates (staff and service users: n = 96)

It is envisaged that the evaluation process will help the local and national team establish whether the programme improves patient care, outcomes and experience and meets the needs of service users.

### **3.1 Cognitive Rehabilitation Intervention**

#### **3.1:1 Recruitment**

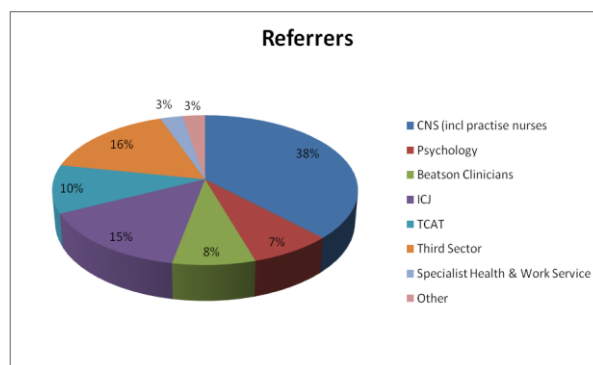
Derived from estimates cited in the psychological literature that 35% of patients who have received cancer treatments will experience some degree of CRCC, it was calculated that this would equate to approximately 2800 patients of the 8000 – 85000 patients attending the Beatson West of Scotland Cancer Centre per year. Given that the group-based cognitive rehabilitation intervention would be targeted at those patients within the 10th percentile, this would equate to approximately 280 patients per year who would be eligible to participate. Therefore, in order to reach this target population of 280 people, it was anticipated that two concurrent groups of up to 17 participants every six weeks could be delivered. Reaching this target was dependent on participant uptake.

Towards the end of year one of the project, discussion was held at the Steering Group (19<sup>th</sup> September 2016) regarding the feasibility of reaching the 280 participant target, given the referral rate. It was recommended that the project lead and manager submit a lessons learned log to the national programme board outlining the rationale for reducing the target figure. The report outlined that the 280 target was based on the potential number of people who could be eligible based on reported prevalence and number of new patients attending the Beatson.

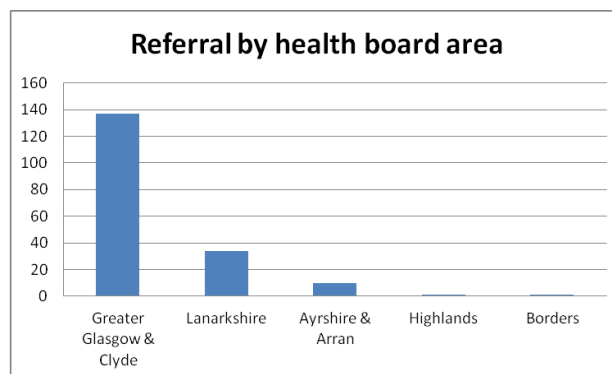
The main issue had therefore been that the referral rate had not been as high as initially anticipated. As cognitive issues (cancer-related cognitive changes) presents, by definition, some time post treatment it proved challenging to access this group of patients who may not be linked in with Acute, 3rd sector or Primary Care services. It was suggested that a revised target of 150 referrals should be submitted. However, concerted effort was made

to raise awareness of the service in all sectors, with a view to maximising appropriate referrals. In the initial stages of the project, referrals were largely received from the Third Sector and the Improving Cancer Journey project. By the start of the second year, referrals from the Clinical Nurse Specialists based within the acute sector increased, resulting in 33% of total referrals received.

The cognitive rehabilitation and support programme received 183 referrals in total from a range of health and social care professionals across acute, local authority and the third sector. As the figure below illustrates, referrals were received by Clinical Nurse Specialists; Clinical Oncologists; Allied Health Professionals; Clinical Psychologists within the Beatson; the Improving Cancer Journey team (Local Authority) and the Third Sector.

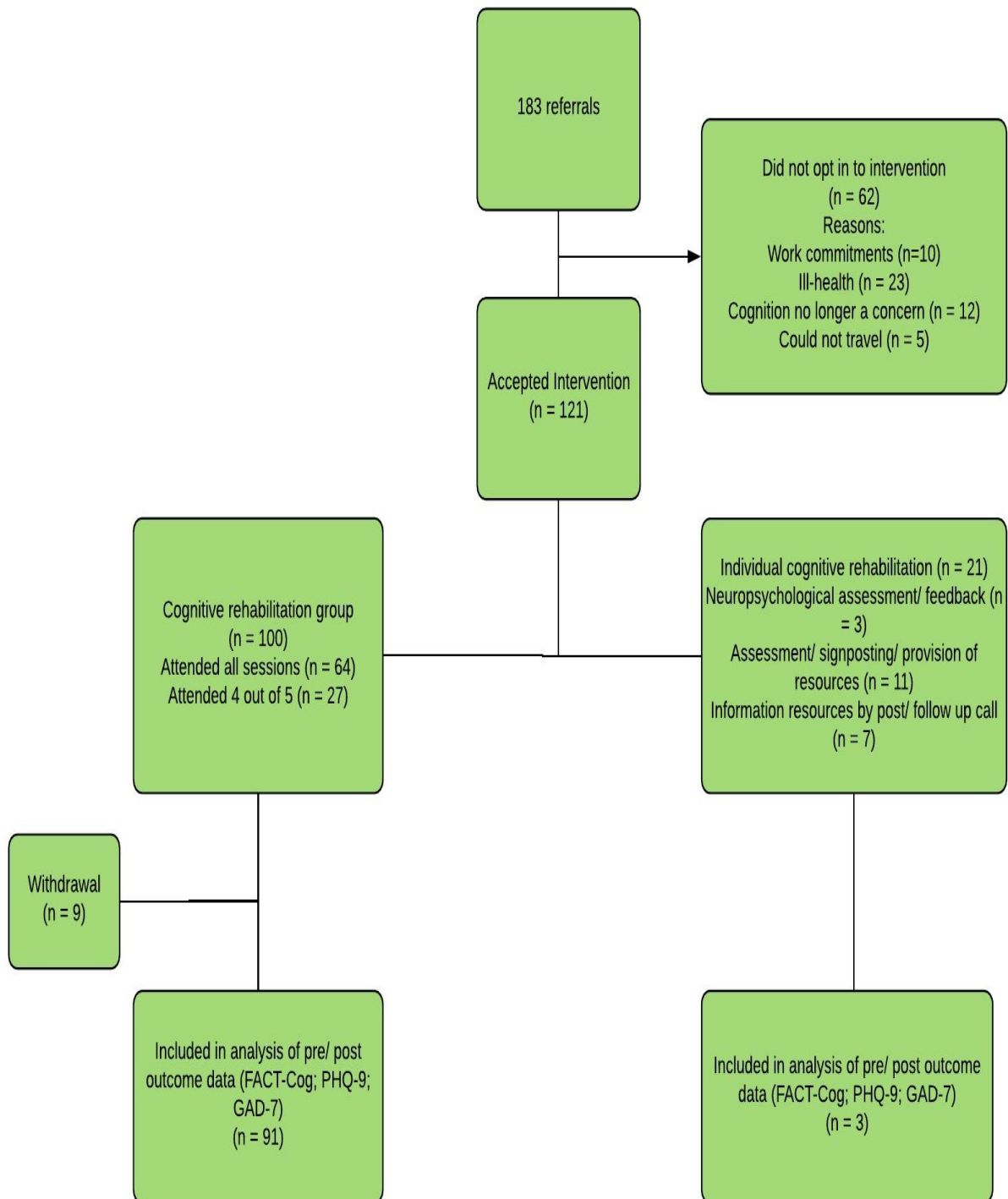


Individuals from across the West of Scotland region accessed the cognitive rehabilitation service, as indicated by the graph below.



As the figure (2) below summarises, 183 referrals were received in total of which 66% (n = 121) accepted a cognitive rehabilitation intervention, either in a group or individual format. Reasons individuals cited for declining the intervention included work commitments; ill-health; cognition no longer being a concern and difficulties in travelling to one of the Glasgow city based venues. The vast majority of individuals (83%) referred to the project accepted a group-based cognitive rehabilitation intervention (n = 100) whereas only 17% (n = 21) chose an individual intervention. The 91% retention rate for the group intervention suggests that this type of support delivered in a group format is an acceptable mode of intervention delivery for this patient population. It was observed that individuals travelled a significant distance to attend the group programme with for example, the Mitchell Library

location attracting participants from North Ayrshire and North Lanarkshire in addition to the NHS Glasgow and Clyde catchment area.



### 3.1:2 Patient characteristics

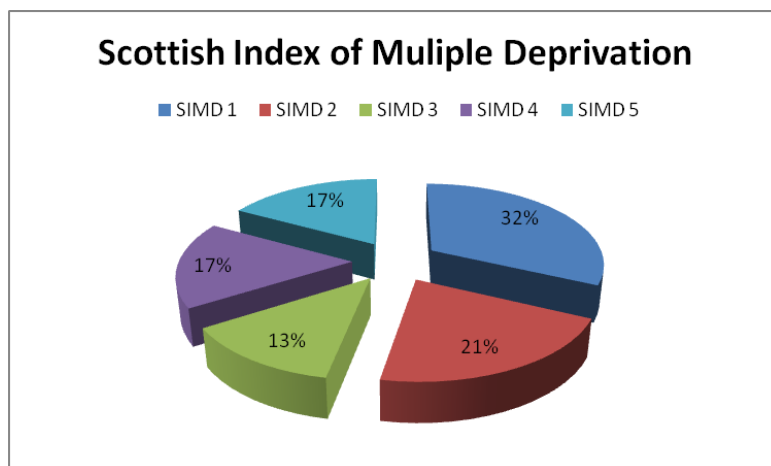
Participant characteristics are summarised below. Contrary to the national trends of relatively equal prevalence rates amongst men (3%) and women (4%) living with cancer (ISD, Cancer in Scotland, 2017), the majority of individuals taking up the intervention were women. Improved five-year survival rates for breast, Non-Hodgkin’s lymphoma and leukaemia (ISD, Cancer in Scotland 2015) indicate that this group of patients will present with long term support needs and is reflective in the project referral rates for breast and haematological cancers. A third of individuals from the most deprived areas were referred to the project, with 68% of participants being of working age.

Gender	Number	Percentage
Male	57	31.15%
Female	126	68.85%

Age	Number	Percentage
20 to 29 years	8	4.37%
30 to 59 years	17	63.94%
60 to 69 years	44	24.04%
70 to 79 years	13	7.10%
80 and over years	1	0.55%

#### Scottish Index of Multiple Deprivation Status (SIMD)

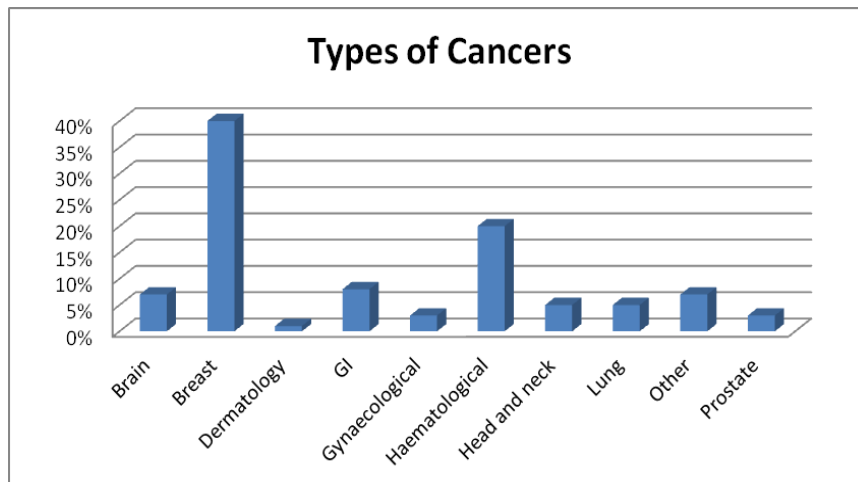
Out of the total 183 referrals to the project, 53% of individuals reside in areas of greater poverty (SIMD 1 and 2).



#### Type of cancer:

As illustrated by the graph below, individuals with breast (40%) and haematological (20%) cancers were most commonly referred to the project for cognitive rehabilitation. This may be indicative of existing support structures such as the breast follow up clinic at Stobhill

Hospital and the Haematology late effects clinic. Based on research estimates, individuals with other diagnoses such as prostate and gynaecological are likely to present with CRCC and could benefit from specific support with these concerns, therefore the referral rate for these tumour groups are not necessarily reflective of need.



Stage of cancer	Number	Percentage
Primary	167	91.3%
Secondary	16	8.7%

#### Living situation:

The largest majority of people referred to the project lived with their spouse/ partner (65.56%).

Living situation	Number	Percentage
Living alone	46	25.56%
Living with spouse/partner	118	65.56%
Living with children/ relatives	16	8.89%

#### Ethnicity:

There was low representation from the Black and Minority Ethnic (BME) communities with only 2% of individuals referred from this ethnic group. The vast majority of people referred were White, Scottish (94.51%) and White, Other (3.30%).

#### Economic activity:

The majority of people referred to the project represented those in employment, including self-employment (49%), with only a third having retired. Challenges with adapting to cancer-related cognitive changes adversely impact individuals not currently in employment

with 17% being referred to the group programme. Given the significant impact CRCC may exert on occupational performance, addressing these concerns for those of working age is pertinent for redressing social inequalities as well as general supportive care in the survivorship stage.

<b>Economic activity</b>	<b>Number</b>	<b>Percentage</b>
<b>Employed</b>	83	46.63%
<b>Self Employed</b>	3	1.69%
<b>Unemployed</b>	30	16.85%
<b>Retired</b>	54	30.34%
<b>Student</b>	8	4.49%

#### **ECOG Performance status:**

The ECOG performance status (named after the Eastern Cooperative Oncology Group) is a functional ability assessment and is an attempt to quantify cancer patient's general well-being and activities of daily life. 0 denotes full health and 5 denotes death. As anticipated, the majority of people (80%) referred to the project reported either full or restricted activity (ECOG 0 & 1) and is shown below:

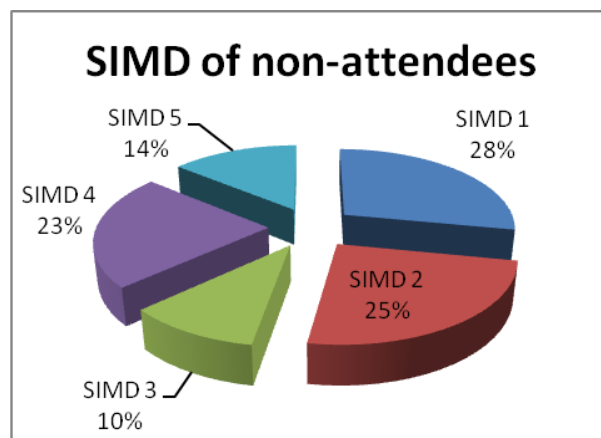
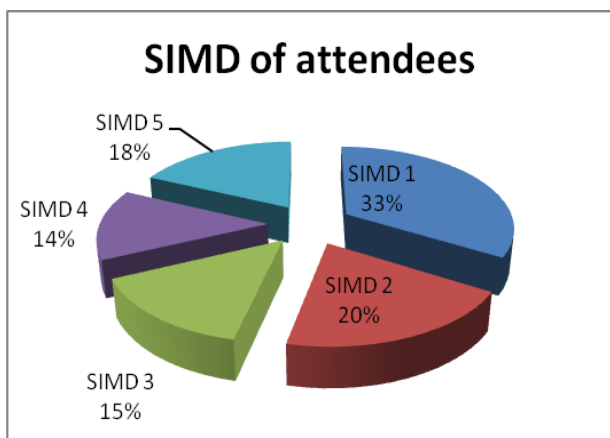
<b>ECOG performance status</b>	<b>Number</b>	<b>Percentage</b>
<b>Stage 0: Fully active, able to carry on all pre- disease performance without restriction</b>	62	34.83%
<b>Stage 1: Restricted in physically strenuous activity, but ambulatory and able to carry out work of a light or sedentary nature</b>	81	45.51%
<b>Stage 2: Ambulatory and capable of all self-care, but unable to carry out an work activities. Up and about more than 50% of waking hours</b>	31	17.42%
<b>Stage 3; Capable of only limited self care, confined to a bed or chair more than 50% of waking hours</b>	4	2.25%
<b>Stage 4: Completely disabled. Cannot carry out any self care. Totally confined to bed or chair</b>	0	0.00%



### 3.1:3 Patient characteristics of non-attendees

There were 62 individuals who did not opt in to a cognitive rehabilitation intervention. As outlined in figure (2) 37% reported ill-health as being a barrier to engagement. The SIMD of individuals who did attend a rehabilitation intervention is shown in the figure below and indicates that those from a lower SIMD were not any less likely to opt out of the intervention.

The emphasis on delivering the group intervention in community settings served to increase access for hard-to-reach populations and contribute to the national agenda of redressing social inequalities. Interestingly, 53% of those engaging with the cognitive rehabilitation intervention live in areas of greatest deprivation (SIMD 1 and 2). Moreover, those not engaging with the intervention are not disproportionately represented from areas of greater poverty. Whilst the numbers for withdrawal are relatively small, it is worth noting that the majority of individuals (70%) not completing the intervention reside in areas of greatest deprivation and thus potential barriers to engagement warrant further consideration.



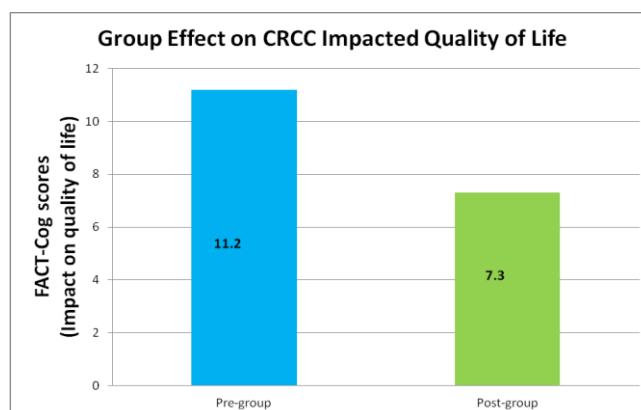
### 3.1:4 Patient reported outcome measures

The functional assessment of cancer therapy – cognition scale (FACT-Cog) was used to ascertain the participants’ perception of cognitive complaints and its impact on their quality of life. The FACT-Cog is a self- report 37 item measure that has been developed as part of the FACT measurement system to assess the nature and severity of cognitive deficits among cancer patients as well as the impact of these deficits on patients’ quality of life.

Outcome measures used to assess the effectiveness of the programme have been the quality of life measure specifically for cognitive functioning (FACT-Cog) and the PHQ-9 and GAD-7 to assess psychological functioning. Ninety-four completed quality of life and psychological functioning outcome measures were collected from individuals who completed the programme, either for individual or group sessions. A two-tailed paired samples t-test was performed on the pre and post outcome data, as summarised in the table below.

Variable	N	Pre-Mean	Pre-SD	Post-Mean	Post-SD	Change Mean	Change SD	P-Value
FACT-Cog	94	12.2	3.8	8.7	3.4	-3.51	7.94	<0.00001
PHQ-9	94	13.0	6.7	11.5	5.8	-1.62	9.29	0.000875
GAD-7	94	12.7	5.6	10.3	4.5	-2.4	7.79	<0.00001

Regarding the FACT-Cog data, the value of t is -8.372052 and the value of p is <0.00001, therefore as depicted in the bar graph below, the result is significant at  $p \leq 0.01$  indicating that the group participants’ distress reduced significantly post intervention.

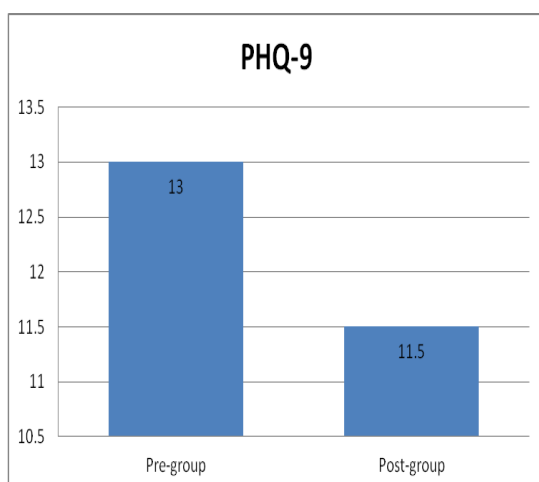


Whilst the FACT-Cog outcome data suggests improvement in the participants’ ability to manage distress related to cognitive changes, generalisability is limited in terms of potential confounding factors. Behavioural interventions entail both specific (treatment) and non-specific (group dynamics; facilitation style) factors and identifying the active ingredients through use of objective measurement tools can prove challenging. Moreover, owing to the

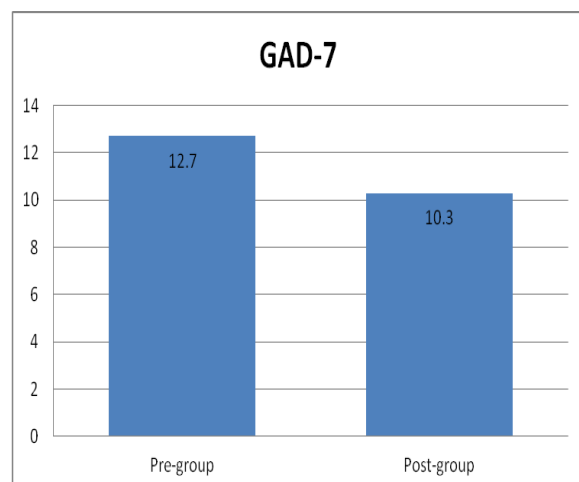
fact that a power calculation was not conducted prior to data collection, the effect size was not established and limits the interpretation of this finding. Future research could benefit from incorporating a control group into the study design in order to ascertain the effective components of the intervention.

Throughout the delivery of the group intervention, ongoing monitoring of the outcome data was conducted. It was observed at the mid-way point that whilst the outcome data largely indicated a decrease in distress regarding cognitive changes, for some participants their FACT-Cog scores increased (identifying an increase in distress about cognitive changes) which may have been due to expectations on the part of the participants regarding the potential for change. A renewed emphasis was therefore placed on managing expectations of participants by sharing with them that the aim of the intervention was to increase one's understanding of CRCC and offer various strategies to manage these changes, rather than necessarily improve cognitive functioning. By means of understanding the nature of the cognitive changes and using coping strategies, it was anticipated that people would cope better and improve quality of life.

On average, participants remained within the moderately severe range of depression following the group programme, whereas participants' levels of anxiety reduced from moderately severe to the moderate range following the group programme. A two-tailed paired samples t-test was performed on the pre and post outcome data pertaining to participants' psychological functioning. As summarised in the previous table and illustrated in the graphs below, individuals' psychological wellbeing improved significantly as a result of participating in the group intervention. As highlighted previously, multiple variables can influence this outcome. Given the clinical interpretation of these findings, namely that participants' anxiety reduced from moderately severe to moderate as a result of the intervention and their mood remained within the same clinical range pre and post intervention, the sample size may have inflated the psychological functioning outcome. Nevertheless, the data suggests that the process of participating in the group intervention may have been conducive to reducing distress associated with cognitive changes and ascertaining the specific effective components of this intervention requires more in depth enquiry such as qualitative feedback.



The value of  $t$  is  $-3.571129$ . The value of  $p$  is  $0.000875$ . The result is significant at  $p \leq 0.05$ .



The value of  $t$  is  $-5.767976$ . The value of  $p$  is  $< 0.00001$ . The result is significant at  $p \leq 0.05$ .

### 3.1:5 Patient Experience

Qualitative feedback was sought from group participants, represented below, where size of word correlates with frequency within the feedback.



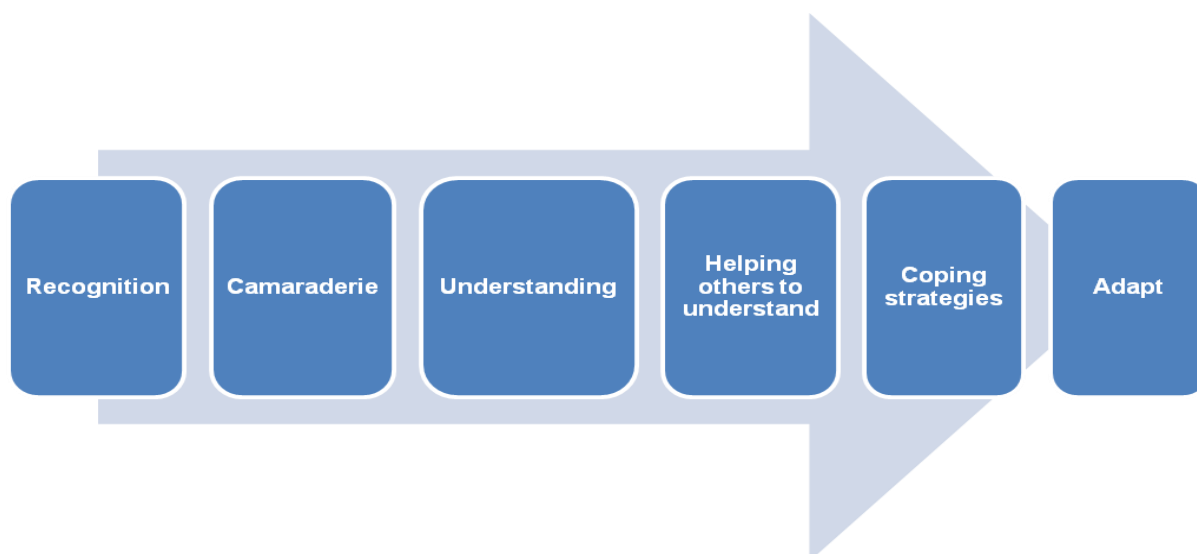
Group participants described benefitting from the programme in helping them understand and better manage cognitive changes post treatment. They perceived that the information about the potential impact of cancer treatment on cognition as being helpful in supporting their psychological adjustment after treatment.

*“It’s not enough. 5 weeks and that’s it. We just scratched the surface. The biggest plus – “I’m not going insane.” (respondent no. 48)*

Participants reported that the psycho-education part of the programme with an emphasis on developing various cognitive compensation strategies has contributed to increasing their confidence in day to day functioning.

*“I feel more confident that I can remember that beforehand I was doing the right things by using brain training apps. And hearing about the theory, as well as seeing others with the same symptoms helped me progress.” (respondent no.6)*

In addition to the participant feedback forms, four individual accounts were qualitatively analysed to ascertain the underpinning processes entailed in adjusting to cancer-related cognitive changes and whether the group intervention played a part in this adjustment. Throughout the duration of the project, seven service users generously gave their time between speaking at conferences and recording their experiences of CRCC for the educational videos. Copies of four of these patient testimonials were used for the qualitative analysis.



**Figure 3: process of adjustment to cancer-related cognitive changes**

As the figure above illustrates, users' perspectives indicate that the information provided on how cancer and cancer treatments can adversely impact cognitive functioning alongside practical strategies of adapting to cognitive changes within a group context is conducive to adjusting effectively with this issue of survivorship. Consistent with the qualitative research (Myers, 2013), individuals benefit from validation of their cognitive concerns and being equipped with the information of how cognitive functioning may be affected. Service users speak about feeling;

*"..relief that this is a 'thing'" (respondent no. 11)*

*" throughout the programme, I did a lot of crying, we were all exactly the same. So, it meant that the relief, I wasn't bubbling because I was upset, I was bubbling because of the relief, knowing I wasn't suffering from dementia." (respondent no. 52)*

Intuitively, discussing these concerns amongst others who have a lived experience of a cancer diagnosis and all that goes with medical treatments can be helpful in this process of adjustment. The group format appeared to provide not only an opportunity to create a shared understanding of cognitive challenges but a sense of camaraderie amongst peers. A sense of humour was often quoted as being pivotal to accepting change and managing accordingly.

*"We bonded whilst sharing tips for getting round problems, laugh at the things we've done. We felt less isolated" (respondent no. 63)*

Without an opportunity to discuss these feelings of unease with others who have gone through treatment, people can be left reeling from the experience and can experience a

sense of disconnection from others, and impaired capacity for enjoyment. The period after completion of treatment is often complex and people can benefit from accessing community supports, particularly those involving meeting others with lived experience of cancer in order to reflect on and process this transition.

A better appreciation of what was “going on” for people in relation to their cognitive functioning led to an enhanced ability to explain this to others, particularly family and close friends. This in itself appeared to be helpful to managing cognitive changes. Sharing analogies of why thinking may be slower for example, provided participants with a new language to increase understanding of those around them. As a result of others appreciating the covert difficulties associated with attention and memory, allowances were made for not being able “to fire on all cylinders” and this also facilitated adaptation and enhanced coping

*“For us, if we’re travelling from Glasgow to Edinburgh, the M8 is now closed. We have to take a different route. At first it’ll be cumbersome and frustrating, but the more often we do it, the easier it’ll become. It may never be quite as quick as taking the M8 but it’ll become routine and good enough - “ the cells that fire together wire together”. I’ve found the M8 analogy a useful way to explain what’s going on to my family and friends, who think I’m generally fine but have developed a tendency to repeat myself.” (respondent no.81)*

Being equipped with the practical information of the cognitive compensation strategies and having an opportunity to test these out throughout the course of the programme and then feeding back to their peers was valued highly by the group participants.

*“We were able to talk about our experiences and all the stupid, silly things we’ve done. I think every one of us came away with new coping strategies.”(respondent no.52)*

*“... tricks, what can I do about it! I actually said to my partner the other night that I’d wait until he’d finished eating his packet of crisps before telling him what I needed to say as the rustling was so distracting!” (respondent no.63)*

*“Write daily lists - I have a list of things to remember to do before I leave the house (is the heating off? do I have a carrier bag?) so I no longer “leave the house in instalments” as my partner describes it!”(respondent no. 81)*

Moreover, they recognised that adapting to CRCC entailed more than applying a set of compensation strategies. By acquiring a richer understanding of cognitive changes and how these applied to their own circumstances, participants were better able to incorporate these into their daily life.

*“We were using reminders, we were using triggers for your mind and mine is as I say, everything pointed to slowing down and regaining my confidence.” (respondent no.11)*

*“Remove the distractions - what affects attention - diet, sleep, fatigue, medication, other people, alcohol, anxiety, stress, self-doubt, environment (noise, temperature) general wellbeing.... These affect everyone’s thinking”. (respondent no.63)*

*“Rest - I now understand why I’m more tired at the end of the day - my brain is working harder than it used to, to do the same things.”(respondent no. 52)*

Participants who engaged with the individual intervention reported similar benefit with regards to increasing their understanding about how cancer-related cognitive changes could impact within work and social environments and how these could be ameliorated. All group participants called for a greater awareness of this issue amongst health and social care professionals, across all sectors, as a means of supporting their adjustment.

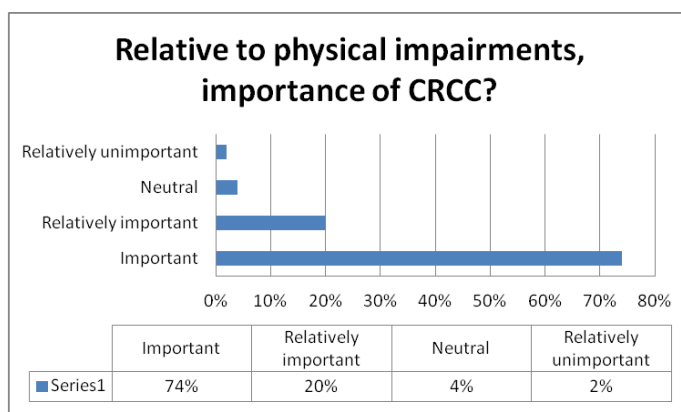
### 3.2 Design of staff training

As delineated in the previous section, data derived from a staff survey and a patient focus group were used to inform the development of the training and information resource aspects of the project. The results obtained from the survey and focus group are included below.

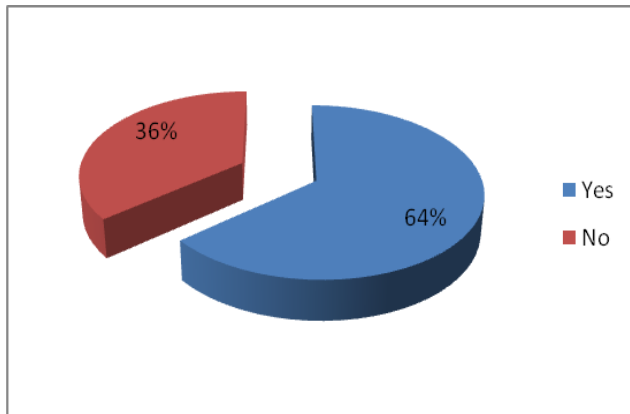
#### 3.2:1 Staff survey results

A staff survey was carried out in April/May 2016 to ascertain current ways of working with regards to supporting individuals with cancer-related cognitive changes. Fifty professionals from health, social care, local authority and third sector settings completed the survey, the results are as follows:

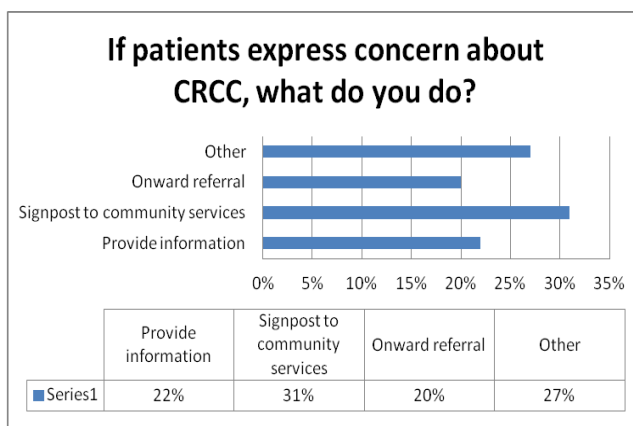
1. Relative to physical impairments after cancer treatment how important do you think cognitive changes are to your patients?



- Do you routinely enquire about patients' cognitive functioning? e.g. memory, concentration, multitasking, planning ahead, remembering appointments.

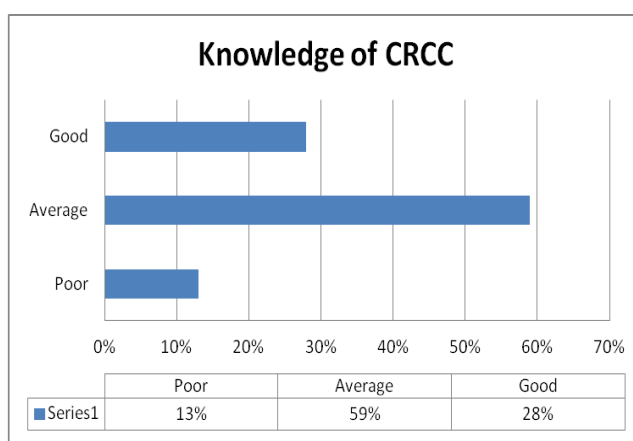


- If patients express concern about their cognitive functioning, what do you do?



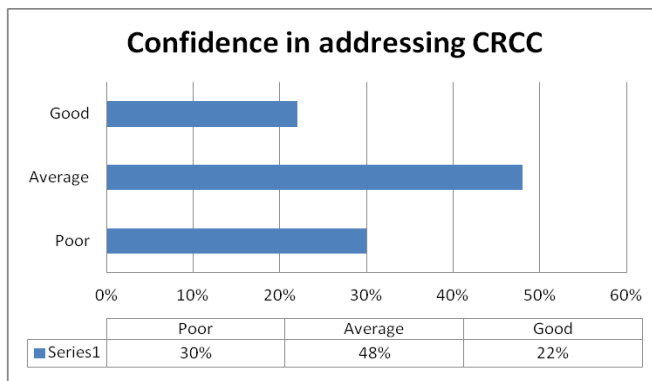
An example of 'other' was normalising cognitive changes and validating the individual's concerns.

- On a scale of 0 – 10, with 0 being the least knowledgeable and 10 being the most, how would you rate your knowledge/ understanding of cancer-related cognitive changes (CRCC)?





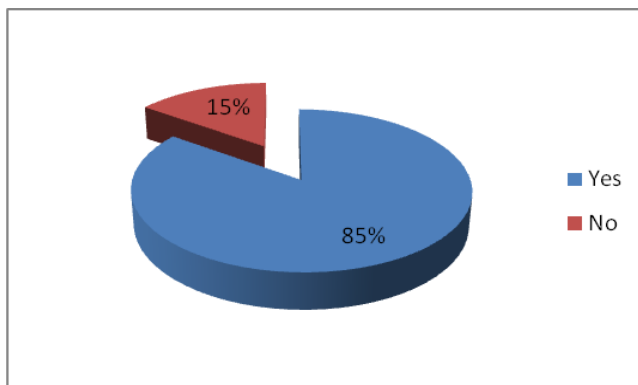
5. On a scale of 0 – 10, with 0 being the least confident and 10 being the most, how would you rate your confidence in providing information and/ or signposting patients to services for support with cancer-related cognitive changes?



6. In your opinion, are there any gaps in service provision for supporting patients with cancer-related cognitive changes?

Yes

No



If yes, what are these gaps in service provision and what type of supports should be offered to patients? The question on identifying any gaps in service provision revealed the following areas of need:

Training/ raising awareness

Clinicians identified a gap in their knowledge base about CRCC and called for specialised training in screening and signposting to the appropriate resources and supports. Respondents acknowledged a lack of confidence in being able to broach this topic with patients:

*“I’ve always known about chemo brain but never known how to address it or what services were available to help.” (respondent no. 4)*

*“It is difficult to find any clear pathway for patients experiencing cancer related cognitive impairment. I also lack confidence in knowing how to diagnose cancer related cognitive impairment when there can be other potential reasons for cognitive changes including things like brain metastases or, for example, in an increasingly elderly population now being offered cancer treatment there are more patients being seen who have age related, organic cognitive impairment.” (respondent no. 33)*

### Resources

Respondents identified both lack of information resources on CRCC as well as lack of understanding about available support services

*“I don't think we ask patients about it enough, because there's a feeling that if they do mention it, there's nothing we can do about it. I think it's massively under-diagnosed, and if there's anything we can offer like cognitive rehab, or emotional support then I think these services should be promoted.” (respondent no. 12)*

### Support

Respondents indicated a gap in both service provision as well as current way of working in supporting patients with CRCC.

*“I think we normalise cognitive impairment rather than doing anything active. It should be formally assessed with a pathway available to direct patients to the right health care professional to help.” (respondent no. 19)*

*“Timely information from oncologists with regard to possible cognitive impairment would help patients have a better understanding of the impact of treatments and would help reduce anxiety around impaired functioning. Patients often report that they have no real understanding of what to expect in terms of how treatments can affect them and some report that, when experiencing side-effects, their first thoughts are that their cancer has returned.” (respondent no. 8)*

The staff survey therefore identified a gap in service provision to support individuals with cancer-related cognitive changes as well as a learning need.

### **3.2:2 Patient focus group results**

Nine individuals who had previously engaged with the cognitive rehabilitation interventions attended the focus group and contributed their experiences of living with cognitive changes post treatment and the types of support they would like to be implemented. Five themes emerged from the group discussion.

#### Invisible side effect

Participants discussed how experiencing cognitive changes can be likened to an ‘invisible side effect’ as it is not always apparent to others that they may struggle with mental tasks.

The questions they have about cognitive changes include; “What am I suffering from?” “How can I get better?” It was felt that information was limited in relation to this aspect of adjusting post treatment.

#### Operationalising Cancer Related Cognitive Changes:

Participants vividly described their CRCC in concrete terms including; “...as if 100 different ideas running around in my head” and “grasshopper in talking.” They spoke about trying to make sense of their symptoms and attributed it to the other side effects such as fatigue. Others noticed that there has been a change to their cognitive functioning although could not identify its underlying cause.

#### Impact of Cancer Related Cognitive Changes:

People discussed the significant impact of reduced cognitive functioning on both their home and work life. Social withdrawal and increased emotional distress were common behavioural and affective responses to experiencing CRCC. Moreover, participants relayed feelings of helplessness as a result of perceiving their experience as not being amenable to change.

*“Losing that control, frightened to say that I wasn’t coping, I thought I was going off my head.”*

*“...terrified that I was going to expose myself, to say the wrong thing.”*

A lack of understanding from employers with regards to flexibility in supporting individuals return to work was a common concern voiced by participants. The focus group called for a greater awareness of this aspect of adjusting post treatment.

#### Forewarned is forearmed:

There was a consensus that being informed about the potential side effects of cognitive changes post treatment was imperative to assist in psychological adjustment. Participants were saying that by and large they were not told about these side effects. Peoples’ experiences were variable, although several Clinical Nurse Specialists raised this as something to assess, others did not. Some people who have gone through treatment more recently were advised of this aspect of survivorship.

Discussion about the potential impact of CRCC would ideally take place at follow up appointments. People talked about preferring to have a conversation about it rather than having to read through leaflets.

#### Relieving anxiety

Having attended the cognitive rehabilitation groups, participants highlighted that normalising CRCC as being a common temporary side effect can be imperative to coping.

One participant described the impact of understanding about CRCC as being critical to relieving anxiety; *“wasn’t going off my head.” “wasn’t losing the plot.”* All agreed that the term ‘chemobrain’ is misleading as people who have not had chemotherapy still experience these cognitive changes. The term can come across as undermining the significance of the functional impact of CRCC.

### **3.3 Delivery of staff training**

Data obtained from both the patient focus group and the staff survey thus highlighted an unmet training need for supporting individuals with CRCC. The patient focus group identified a need for a greater awareness amongst health and social care professionals about some of the potential cognitive changes following cancer treatments. The focus group participants suggested that education events could be arranged to raise awareness of this issue. To this end, the project clinician submitted a Macmillan Group Grant application leading to financial support to run an education event.

A one day conference with the aim of raising awareness of cancer-related cognitive changes (CRCC) secondary to cancer treatment amongst health and social care professionals was held on 24<sup>th</sup> April 2017 at the Glasgow Pond Hotel, financially supported by Macmillan Cancer Support (see Appendix VI). The conference entitled *“Memory and concentration changes after cancer treatment. What do we know? What can help?”* was based on a co-production approach whereby the lay representatives from the project’s steering committee; Catriona Gorton and Diana Johnston were instrumental in the planning and implementation of the education event, and four service users presented about their experiences of living with and adapting to memory and concentration changes. Catriona Gorton was the chair of the conference and Diana Johnston represented the Cancer Experience Panel in presenting about the panel’s role within the national TCAT programme. Professor Robert Ferguson, an expert from the USA in cancer-related cognitive changes spoke about his research and clinical trials investigating psychological interventions to support individuals with CRCC.

The cancer-related cognitive changes video, which includes two service users (Jess Campbell and Dougie McCall) speaking about their experiences of participating in the group programmes as well as Madaline Alexander, Cancer Support Scotland presenting about the topic, was launched at the conference. Positive feedback was received about the video and delegates suggested wide circulation of this audio visual resource to increase awareness of CRCC, particularly amongst employers.

The conference was well attended with 96 delegates representing clinical nurse specialists (Breast; Urology; Haemato-oncology; Colorectal; Lung; Head & Neck); Clinical Psychologists (from a range of specialities: Older Adults; Oncology; Cardiac Rehabilitation; Neuropsychology); Third Sector (Breast Cancer Care; Cancer Support Scotland; Accord Hospice; Ayrshire Cancer Support; Ayrshire Hospice; Maggie’s Centre Dundee); Local Authority (Improving Cancer Journey; Glasgow City Council Libraries); Macmillan and service users. A range of NHS health boards were represented including; NHS Greater Glasgow and Clyde; NHS Lanarkshire; NHS Ayrshire and Arran; NHS Forth Valley and NHS Fife.

There was an 80% response rate to the conference feedback questionnaire which indicated that 99% of those surveyed agreed/ strongly agreed that they were satisfied with the quality of the conference. 95% reported that the conference met their needs and expectations.

Which session did you find the most helpful and why?

All of the presentations were received well and the round-table discussions session provided an opportunity to voice their opinions and ideas about how best to support individuals with memory and concentration changes post treatment. Members of the steering group generously offered their time to facilitate table discussions and ensured main discussion points were captured accurately. Anecdotally, it appeared that there was a good mix at the tables of health, social care and local authority professionals as well as service users which in turn enriched the discussions. Feedback about the sessions included:

*"It is always so powerful hearing about patient affected by cancer voice. All of the speakers were excellent. Very good day and hopefully this will set the scene for future work and support for people in this area."*

*"The 2 sessions by Professor Ferguson were very educational with practical advice along with enlightening research"*

*"All of the day gave me food for thought and desire to change my practice."*

*"All presentations very helpful. Good mix of talks from both service providers and service users. Round table discussions very informative."*

*"Very informative – can't guarantee I will remember it. It was good to hear fellow cancer patients giving their experiences and the speakers who spoke passionately about their work. The cartoons were excellent and I didn't realise how many items on the posters I totally agreed with."*

Overall, what do you feel you have gained from attending the TCAT cognitive rehabilitation conference?

*"Greater understanding of extent of problem. Increased confidence in discussing this with patients and families/carers and therefore developing management plan etc."*

*"User perspectives – very useful and thought provoking. Generating questions about my existing practice."*

*"Increased awareness of the issues and more comfortable with discussing issues with patients. Good networking and sharing experience with other delegates."*

*"To be more accepting of chemobrain – to understand it has a big impact on patient's quality of life."*

*"I have gained a further understanding of the problem and steps being taken to support patients like myself. I have further confidence to speak about it."*

In addition to the conference feedback form, delegates were asked to complete an online survey to assess whether the event met their training needs and the extent to which they felt competent to support individuals presenting with mild to moderate levels of CRCC. The survey indicated that the event raised awareness of this issue and several health and social care professionals mentioned they would include assessment of CRCC within their roles supporting individuals after cancer treatment.

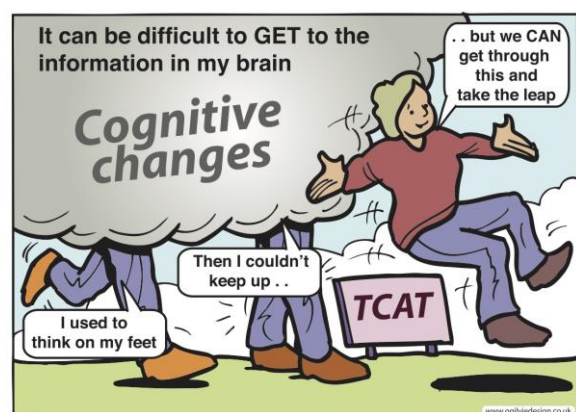
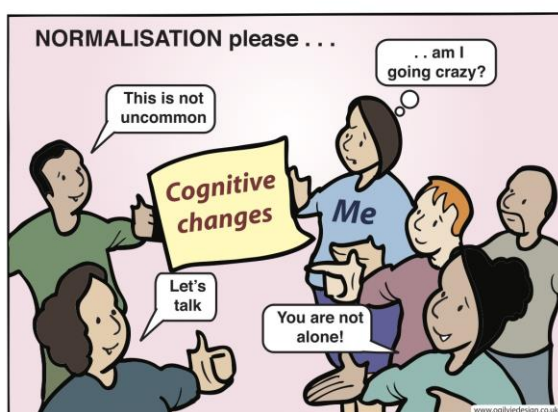
An integral part of the programme included seeking delegates' views on how support for individuals presenting with CRCC could be sustained beyond the project. The round-table discussions entailed discussing ways of embedding support within existing services for individuals presenting with CRCC beyond the duration of the project. The two questions discussed were:

- Information giving: what information about memory and concentration changes after cancer treatment should I provide to the people in my care?
  - Level of detail?
  - Timing of providing information? e.g. pre or post treatment
- What will you take away from this conference and incorporate into your daily practise?

The consensus from the round-table discussions pertained to sharing the learning from the project with a view to rolling out the service to other health board areas.

### Key messages

Throughout the duration of the conference, Graham Ogilvie, Cartoonist, visually captured themes arising from the presentations and discussions in cartoon format. Graham then displayed these cartoons in the conference room and delegates were asked to rate the extent to which they agreed with the messages portrayed in these images.



The themes ranged from the challenges associated with the psychological adjustment after active cancer treatment through to ways people have managed this adjustment process. In terms of understanding and adapting to CRCC, the service users who presented at the

conference as well as contributed through their discussions raised the importance of increased understanding from professionals across all sectors in recognising that CRCC can impact negatively on their quality of life post treatment.

### **3.4 Development of the CRCC self help materials**

The introduction to cancer-related changes video was launched at the project conference on 24<sup>th</sup> April 2017. The video features two service users; Jess Campbell and Dougie McCall who speak about their experiences of living with and adapting to cognitive changes and Madaline Alexander, Operations Manager from the Calman Centre, Cancer Support Scotland explains about the causes of CRCC. In response to feedback from the steering group, two additional videos were produced in liaison with NHS Greater Glasgow and Clyde Medical Illustration to provide further information about the cognitive compensation strategies. Victoria Grant, Assistant Psychologist explains about the typical attention and memory difficulties associated with cancer treatment and how these can be best managed. The three videos are easily accessible through the NHS Greater Glasgow and Clyde's YouTube channel. The 638 views to date, plus anecdotal evidence, suggests that these videos provide a useful resource for individuals and staff. In addition, the self-help materials sub-group, as delineated in the previous section, recommended to augment the existing literature which resulted in the A5 CRCC booklet incorporating the cognitive strategies and illustrated by the cartoons drawn by Graham Ogilvie from the project conference. (See Appendix VII).

## **SECTION 4 – DISCUSSION**

The cognitive rehabilitation project aimed to develop and test a new model of care to support the psychological needs of individuals adjusting to cancer-related cognitive changes (CRCC). As elucidated in the 2016 cancer strategy, provision of support services tailored to individual needs, alongside developing capacity in staff groups to address unmet needs of people living with and beyond cancer are government priorities. It is these aspects of improving patient care and developing capacity which underpinned the aims of the project. It was envisaged that patient care regarding support for cancer-related cognitive changes would be achieved by:

- Increasing awareness of CRCC amongst health and social care professionals within an oncology acute and community setting;
- Improving understanding amongst health and social care individuals of the potential impact of CRCC on individuals' quality of life;
- Improving information provision about CRCC and signposting to support services;
- Improving outcomes on the quality of life measure specific to cognition; reduced psychological distress and reduced impact on daily functioning.

Within the broader context of the national TCAT programme, reflections about the current project will focus on the extent to which it contributed to the transformational change care agenda. The West of Scotland Cancer Network (2017), highlights that the success of the national TCAT programme will be measured against the following criteria:

- Initiating and embedding an integrated and sustainable approach to the provision of care involving health, social care and third sector partners that drives a shift in focus from treating the disease to health and wellbeing;
- Creating a culture of confidence in patients and professionals, which supports people to regain control of their lives, facilitates self-management, develops new approaches to surveillance and reduces unnecessary reviews; and
- Facilitating the establishment of shared decision-making with patients in cancer follow-up programmes that promotes co-design of high quality, safe and person-centred care.

The evaluation of the current project therefore sought to ascertain the level of impact, if any, on developing a sustainable model of care for cognitive rehabilitation that improves the lives of people after cancer treatment.

### **4.1 Effectiveness of cognitive rehabilitation intervention:**

In an effort to ascertain the effectiveness of the cognitive rehabilitation intervention, patient self reported outcome measures were collected prior to and after the intervention. In addition, qualitative data was collected from a patient focus group interview coupled with patient testimonials. Whilst the outcome data of the FACT-Cog, PHQ-9, and GAD-7 indicate a reduction of distress related to cognitive changes as well as improvement in psychological functioning, the specific mechanisms underpinning improvements are unclear. The intervention was not conducted as part of a clinical trial, rather as a service development



activity and therefore lacks rigour with regards to research design, such as the absence of a control group to act as a comparison to the treatment group. Nevertheless, the combination of quantitative and qualitative data indicates clinically relevant findings.

The quantitative data is interpreted cautiously given the inherent challenges in assessing the efficacy of behavioural interventions. Patient self report outcome measures provide a 'snapshot' of time pertaining to patients' experience of a behavioural intervention rather than assessing the complexity and long-term nature of the intervention. It has been argued that there are important aspects of evidence related to psychosocial and health interventions that are not covered by the established criteria for evaluating medically oriented evidence. Clinical trials of psychosocial interventions have often reported minimal or no statistical significance although patient self-reports can indicate substantial clinical benefit (Fonnebo et al. 2007). Therein lies the value of attending to the lived experience of individuals when assessing the effectiveness of behavioural treatment.

The qualitative data therefore elucidates some of the potential processes at work; namely that recognising and responding to cognitive difficulties is conducive to individuals' adjustment after treatment. This finding corroborates the qualitative research literature which identified that validation of patients' cognitive concerns coupled with the provision of information and support to adapt accordingly, is essential to adjustment (Von Ah et al., 2013). Moreover, as highlighted in the survey conducted with clinicians in this project, the more that both staff and patients are aware of this issue, the better equipped they will be to manage it. For this reason, developing capacity within health and social care professionals by enhancing their understanding of the extent and nature of CRCC, coupled with increasing their confidence in discussing this aspect of adjustment was an essential component of developing the CRCC model of care.

#### **4.2 Social inequalities:**

The data indicates that those who participated in the cognitive intervention benefitted in terms of experiencing a reduction in reported levels of distress and feeling supported in their adjustment after treatment. A core theme however arising from the 2016 cancer strategy relates to increasing access to information, advice and support, particularly with regards to reducing inequalities. As outlined in the results section, whilst just under 50% of participants from the most deprived areas (SIMD 1 and 2) engaged with the service, over half of those referred to the intervention who did not then engage, were represented from those areas of greater deprivation. Additionally, amongst the individuals who withdrew from the intervention, 70% (SIMD 1 and 2) were from the most deprived areas, which raises the question as to whether significant barriers prevented these individuals from engaging with this support. The reasons individuals gave for not opting into the intervention pertained primarily to ill-health and distance and therefore may be amenable to resolution. For instance, alternative models of delivery e.g. use of information technologies, could provide a means to redressing this inequality gap.

In an attempt to ascertain any barriers to engagement with the group based intervention within a community setting, the project clinical psychologist distributed the CRCC booklet to patients who did not opt in, and asked whether they would be willing to complete a short

survey. Unfortunately, out of the 38 booklets sent, no individuals responded to the survey. Non-engagement with this survey can be attributed to a range of factors and indicates an area of development to develop innovative and flexible approaches to ensure access for hard-to-reach groups.

### 4.3 Readiness to engage:

An essential component of the intervention entailed managing the expectations of group participants with regards to improvements in cognitive functioning. It was emphasised in the introductory session that the intervention aimed to provide information and strategies to support emotional adjustment after cancer treatment. It was not intended to ameliorate cognitive changes but rather reduce the distress associated with these changes and thereby enable those affected to manage more effectively. Discussions within the steering group focused on whether increased readiness to engage with the intervention was correlated with the type of service initiating the referral such as the ICJ, acute CNS, consultant etc. It was postulated that individuals who had engaged with a holistic needs assessment through contact with the ICJ or their clinical nurse specialist for example, where other practical/ financial needs could be addressed may have enhanced readiness to engage with a psychological intervention aimed at supporting their emotional needs, specific to cognitive changes. Referral rates were compared by referral source in relation to the number of individuals who did not opt in to the intervention. As illustrated in the table below, the rates were relatively comparable across referral source with the exception of the third sector referrals. Therefore no particular influencing factor in relation to exposure to previous HNA assessment was identified in individuals' readiness to engage with the cognitive rehabilitation intervention.

Speciality	Attended	Not attended
<b>CNS</b>	43.29%	37.50%
<b>ICJ</b>	11.34%	21.42%
<b>TCAT</b>	9.27%	10.71%
<b>Third Sector</b>	18.55%	7.14%
<b>AHP</b>	7.21%	8.92%
<b>Clinical Psychologist</b>	7.21%	10.71%
<b>Medical Consultant</b>	3.09%	3.57%

Referral rates alone are unlikely to explain the complexity of the factors entailed in participants' readiness to engage with a psychological intervention. The recent secondary analysis report of the Scottish Cancer Patient Experience Survey (2017) may shed light on some of the factors which influence individuals' experience of cancer care. The analysis highlights that not having a care plan and not being informed by health and social care professionals about the impact of cancer on quality of life; lack of information about peer support groups and financial/ benefits assistance are influencing factors in individuals' negative experience of cancer care. The survey analysis further indicates that lack of an easily contactable clinical nurse specialist and multiple conditions adversely impact their adjustment in the post-treatment phase. Haematological cancer patients were amongst four tumour types who were more likely to report a positive experience of cancer care with

regards to being supported with the emotional and practical impact of their diagnosis on quality of life. Interestingly, the second highest rate of referrals within this project was derived from the haematological clinical nurse specialists.

#### **4.4 Developing capacity:**

One of the aims of the project set out to increase awareness of CRCC amongst health and social care professionals, as well as professionals working in local authority, occupational health and employment settings. Alongside the conference and raising awareness sessions with staff groups, it was apparent that the cumulative effect of positive patient reports from engaging with the programme led to a richer understanding of the impact of CRCC on patients' quality of life. This increased understanding correlated with a greater willingness to raise CRCC as part of their roles in supporting patients with adjustment after treatment. Feedback from the conference indicated that increased knowledge about CRCC, coupled with appreciating the impact on an individual's quality of life effected change in clinicians' willingness to incorporate this aspect of care into their daily practise. Moreover, conference delegates called for greater equity of access to support across Scotland for patients presenting with CRCC. Any efforts to share the learning of the intervention specifics with other health board areas were welcomed. In order to build on this momentum, sustainability plans were discussed at steering group level and follow up discussions with the TCAT programme managers, leading to the development of the CRCC Train the Trainer event for clinical/counselling psychologists and rehabilitation specialised occupational therapists. The Train the Trainer event aimed to share the findings of the TCAT cognitive rehabilitation project and specifically transfer learning and resources to enable clinicians to deliver CRCC interventions in their services.

The self-management training aimed at third sector and clinical nurse specialist colleagues further strengthened their capacity to support their patients with CRCC difficulties. Feedback illustrated that the CRCC patient booklet and patient videos provides vital information resources for use in their roles supporting patients. Clinicians reported that they have long been aware of CRCC presentations and its impact on their patients' quality of life. However, they described lacking confidence to broach this topic with them. Clinicians spoke about valuing access to CRCC information resources and support services as part of their provision of holistic patient care.

Occupational Therapy colleagues within the oncology acute setting attended the project conference with a view to increasing their understanding of cognitive issues post treatment and how individuals may be supported. Additionally, the CRCC information resources can be incorporated within their existing services providing support to inpatients as well as outpatients through their fatigue management clinics.

#### **4.5 User involvement:**

From the outset an emphasis was placed on ensuring the service user voice informed the development, implementation and evaluation of the project's activities. Whilst a co-productive approach was not fully realised, steps were taken towards adopting co-productive principles. Involvement of the steering group lay representatives, Catriona

Gorton and Diana Johnston in the development of the project information resources, i.e. co-facilitating the focus group and the self-help materials subgroup enhanced the quality of work produced and ensured it met the needs of those accessing services to support them with cognitive changes. The project clinician worked alongside the lay representatives in the planning and running of the CRCC conference. The contribution of the lay representatives, coupled with the service users who generously gave their time to present narratives about their experiences enriched the programme, which was reflected in the delegates' feedback.

In the latter stages of disseminating the learning and the self-help resources, Andrea Joyce as a service user of the cognitive group approached the clinical psychologist to offer her input for co-facilitation of the training sessions in order to ensure the user voice was an integral part of the training. The project clinical psychologist and Andrea Joyce co-facilitated the self-management training aimed at third sector health and social care professionals.

#### **4.6 Limitations of project:**

It was envisaged that the delivery of the cognitive rehabilitation interventions would be within a stepped care model, whereby a triaging process would enable patients who had been identified/assessed as having mild cognitive deficits post-treatment being directed to lower intensity support via self-help information and guidance, and those with more significant difficulties being referred to the intervention. This required additional cognitive screening by professionals within the existing supports and structures e.g. the holistic needs assessments performed by the Improving Cancer Journey team, Occupational Health assessments, Welfare Rights Officers, and follow-up appointments with medical/nursing staff. However, in reality, resource constraints prevented the implementation of the screening process, thereby resulting in the project clinician tasked with screening potential participants prior to the intervention. In the initial stages of the project, individuals underwent a pre-assessment appointment to ascertain their support needs. However, this was unsustainable in the long-term given the limited capacity of the project for clinical input.

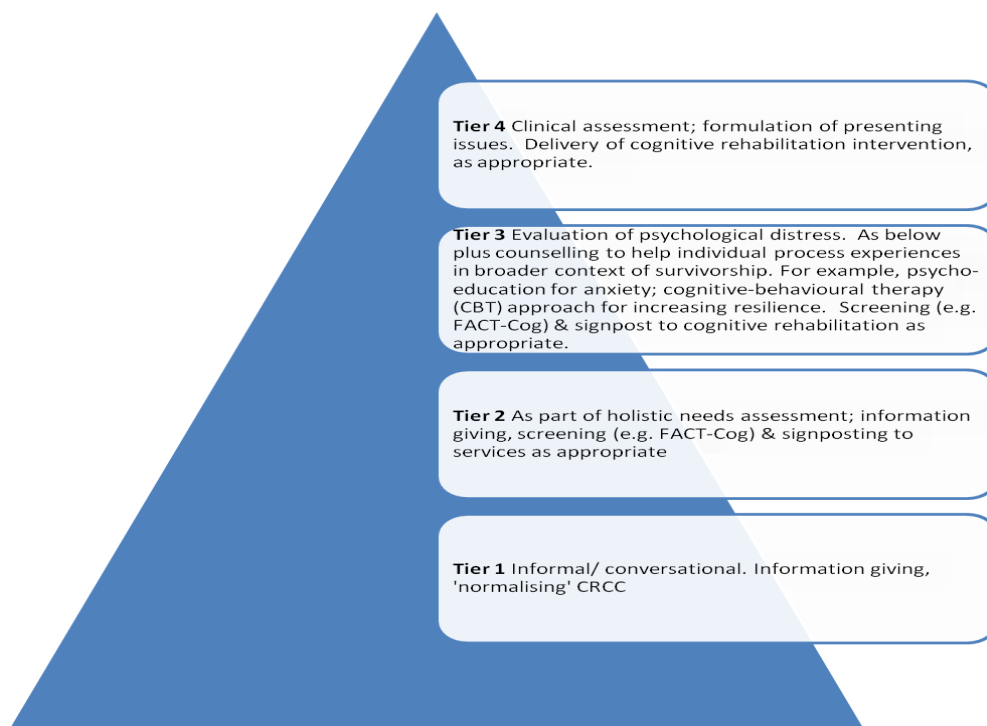
Lack of feedback from individuals who did not opt in to the intervention or from those who withdrew poses a limitation for the evaluation. Referrers were contacted about the individuals who withdrew from the intervention to ensure the continuity of support. However, no specific feedback was obtained regarding the suitability of the intervention for these individuals. Moreover, there was no response to the survey sent to individuals who did not opt in to the intervention initially.

#### **4.7 Recommendations and next steps**

The response from both individuals with a cancer diagnosis and the professionals who support them indicated that innovative approaches were required to redress the gap in service provision for cancer-related cognitive changes. The current TCAT project proposed to develop and test a new model of care to address the cognitive support needs of individuals following cancer treatment which entailed:

- patients being asked about their cognitive functioning as part of their follow-up care e.g. as part of their holistic needs assessment (HNA);
- patients being provided with written and audio-visual information about cancer-related cognitive changes and signposted to further support, if appropriate;
- patients being offered an assessment of their cognitive functioning and if appropriate offered a cognitive rehabilitation intervention to support their needs.

The staff training component of the project appeared to increase awareness and understanding of the potential adverse impact of cancer-related cognitive changes on individuals' wellbeing and daily functioning. This was reflected in the consistent rate of referrals throughout the duration of the project and particularly with an increase in referrals from the Clinical Nurse Specialists across cancer site specific teams. As the project was drawing to a close, clinicians queried whether plans were being developed to extend the service of cognitive rehabilitation as they had frequently signposted individuals to the service following completion of a holistic needs assessment and/ or through routine clinical practice. Furthermore, the engagement, retention and attendance rate of the group cognitive rehabilitation intervention suggests that it is a viable option for individuals presenting with cognitive changes. Collectively, this data suggests that a new model of care as depicted in figure 4 below may be amendable to embedding within existing practice as a means of enhancing after cancer care for those presenting with cognitive difficulties secondary to their cancer treatment.



**Figure 4: A New Model of Care - responding to cognitive support need**

In line with the WoSCAN Psychological Therapies and Support Framework (2015), the stepped care model outlines the different levels of support with CRCC which may be required by people affected by cancer and how the varying levels of support could be implemented in accordance with the competencies of staff. It is recommended that the

new model of care for supporting individuals with cancer-related cognitive changes is implemented as follows:

- Health and social care professionals operating at Tier 2 such as clinical nurse specialists or holistic needs advisors from the Improving Cancer Journey (ICJ) team may identify CRCC as part of their holistic needs assessment and are in a position to provide information about the condition, normalise its occurrence and signpost to further support.
- Clinicians within Tier 3 such as trained counsellors can enable individuals' process their experiences in the broader context of survivorship and apply cognitive behavioural therapy (CBT) approaches to increase resilience and improve quality of life and refer to cognitive rehabilitation as appropriate.
- Counselling or Clinical Psychologists operating at Tier 4 utilise clinical assessment, formulation and intervention competencies to fully ascertain the overriding presenting issue and how best to meet the support needs of the individual. Cognitive rehabilitation interventions (group and individual) would be included within this level of service delivery.

The table below details examples of clinical cases requiring different levels of support with cognitive rehabilitation, that is; individual, group or neuropsychological assessment in order to assist health and social care professionals assess and refer patients appropriately given presenting criteria.

Clinical case examples:

**Individual Cognitive Intervention**

Mrs Brown is a 63-year old woman with a diagnosis of grade two ovarian cancer. She received a total abdominal hysterectomy and bilateral salpingo-oophorectomy followed by six cycles of adjuvant chemotherapy in December 2012.

She reports difficulty in managing the demands of her administrative role in a busy open-plan office environment. She perceives that she is unable to process information quickly, which in turn adversely impacts on her ability to carry out routine tasks which she previously carried out with ease. She reports additional work pressures arising from low staffing levels and therefore unwillingness from her employer to adapt her workload and implement reasonable adjustments. She describes being unable to sustain her initial efforts with settling back to work and has noticed a knock-on effect to her mood. She describes generally managing in her home environment and utilises strategies well such as chalkboard/ diary.

An initial assessment identified long-standing anxiety and depression, and whilst Mrs Brown acknowledged that her mental health is currently stable, she identified that her social anxiety may present a barrier to participating in a group intervention. Given that she would likely benefit from the cognitive rehabilitation, an option of an individual intervention was offered.

**Assessment:**

An individual cognitive rehabilitation intervention would entail an initial assessment consisting of:

- Mood screening (depression and anxiety measures);
- Cognitive screening (Montreal Objective Cognitive Assessment – MoCA);
- Impact on quality of life (FACT-Cog);

**Intervention:**

Mrs Brown would be provided with feedback about the screening results, psycho-education in line with information taught in the TCAT Cognitive Group, and discuss coping strategies. An individualised approach allows for flexibility in terms of being able to ascertain specific circumstances cognitive changes are most disruptive to and address how these can best be managed e.g. through communicating needs with relevant parties (e.g. employer) and utilisation of cognitive compensation strategies. Additionally, the importance of employing anxiety management techniques and general self-care strategies, such as mindfulness, would be emphasised.

**Group Cognitive Intervention**

Mr Jones is a 58-year old man with Non-Hodgkins Lymphoma, treated with six cycles of R-CHOP chemotherapy with high dose systemic Methothrexate in 2008 and following a relapse in 2009 treated with two cycles of R-DHAP and BEAM autograft.

He reports difficulty in sustaining and dividing his attention between tasks and expressed concern as to whether this could adversely impact his ability to carry out his duties as a security officer. He has recently returned to work after a significant period of leave and is particularly concerned that he will struggle to keep up with the pace of work and learn the new computer systems. He describes feeling anxious about 'keeping up appearances' with his line manager and reluctant to request any adjustments to his role. He reports withdrawing from family and friends to avoid any embarrassment in not being able to keep up with the thread of a conversation and/or not finding the right words to express himself. As a result, he has noticed that he his mood has dipped in recent months and feels socially isolated.

**Assessment:**

Prior to offering the group cognitive rehabilitation intervention, an initial assessment consisting of:

- Mood screening (depression and anxiety measures);
- Cognitive screening (Montreal Objective Cognitive Assessment – MoCA);
- Impact on quality of life (FACT-Cog);

would be carried out. If the cognitive screening indicated significant cognitive difficulties, further assessment would be offered and advised that a group intervention would not be appropriate.

**Intervention:**

The group cognitive rehabilitation intervention entails five weekly two-hour sessions covering the following topics:

- How does cancer and cancer treatments affect cognitive functioning? – the first

session highlights that cognitive changes can be a condition in its own right and addresses some of the underpinning causes of these changes;

- Attention/ concentration – what it is and how to improve it;
- Memory – what it is and how to improve it;
- Executive function (planning and organisational skills) – what it is and how to improve it;
- Summary session – open to family and friends in order to increase the understanding of significant others and thereby provide additional support for adapting to and managing cognitive changes.

The peer support element which is integral to the group interventions can provide opportunities to validate cognitive concerns and increase confidence to try out coping strategies within the group environment. Employing anxiety management techniques and general self-care strategies are also encouraged. Self-help resources (information booklet and videos) can assist with retaining the information, as well enabling others to understand how cognitive changes can disrupt day to day functioning.

### **Neuropsychological Assessment**

Mr Smith is a 23-year old man with a grade two astrocytoma, debulked, followed by radiotherapy ending in March 2016.

He reports difficulty remembering details of conversations and word finding issues, resulting in frustration and a reduction of confidence when speaking to people. He reports that his mother has noticed some changes in his memory, but particularly his frustration. He describes these changes as arising in the last six months, and being inconsistent and variable depending on the day.

Mr Smith currently attends university four times a week, and having recently moved into his own apartment, spends much of his time organising his new home, and attending the gym. In order to manage his current cognitive difficulties, he keeps a weekly planner which he reports relying on heavily. He describes his social life and support as ‘good’ and ‘strong.’

#### **Assessment:**

A neuropsychological assessment would entail mood screening measures and standardised tests:

- Mood screening (depression and anxiety measures);
- Impact on quality of life (FACT-Cog);
- National Adult Reading Test (NART) to ascertain pre-morbid intellectual ability;
- Repeatable Battery for the Assessment of Neuropsychological Status (RBANS) to assess cognitive strengths and weaknesses;
- Additional executive functioning (planning/ organisational) tests e.g. the Key Search Test, Zoo Map Test (from the Behavioural Assessment of Dysexecutive Syndrome - BADS);
- Trail Making Test and Coding WAIS-IV sub-test to assess visual attention switching and processing speed.



**Intervention:**

Mr Smith would be provided with feedback about test results, psycho-education in line with information taught in the TCAT Cognitive Group, and discuss coping strategies. Furthermore, he would be provided with self-help resources and a written summary of his neuropsychological profile outlining how he could play to his strengths and incorporate the strategies into his daily routine. The results of the neuropsychological testing could provide a cognitive profile that may be utilised as a baseline for future assessments.

**Recommendations for TCAT Programme Board:**

A consistent theme emerging from the project was a call for greater awareness of cancer-related cognitive changes, especially within employment settings. Given that 70% of participants were of working age, this is an important area of unmet need in cancer survivors. To this end, it would be beneficial for the following actions to be implemented:

- Liaise with the regional cancer networks to raise awareness of the potential impact of CRCC on patients' quality of life in the survivorship phase;
- Raise awareness of the availability of the CRCC information resources (paper and audio-visual) across the regional cancer networks;
- Liaise with the communications departments within NHS Scotland regarding the provision of information about cancer-related cognitive changes.
- Support NHS Psychologists and Specialist OT's working within oncology services to deliver the CRCC intervention on an ongoing basis, in partnership with third sector colleagues. This will require support to train other members of staff
- Support the ongoing provision and revisions of CRCC patient information.
- Support the ongoing delivery of a "train the trainers" model of CRCC training, possibly in conjunction with NES.

**4.8 Conclusion**

The project was successful in achieving what it set out to do in relation to its three primary aims i.e. to deliver cognitive rehabilitation support; to develop supplementary CRCC resources and to liaise with a variety of health and social care professionals across care settings in developing their capacity to support individuals with this aspect of survivorship. Within the broader context of the national TCAT programme, the project aimed to initiate and embed an integrated and sustainable approach to support provision specific to CRCC in collaboration with health, social care and third sector partners. Echoed in the recent publications of *Realistic Medicine* (2016) and *Realising Realistic Medicine* (2017), co-ordinating care across sectors and ensuring a flexible approach in the delivery of this care is essential in order to appropriately meet the needs of individuals accessing these services. The conditions required for implementing this approach entailed communication; connection; collaboration and attending to the culture within existing services. These conditions underpinned the approach in ensuring sustainability of the new model of care. It is envisaged that the self management and train the trainer sessions will serve to develop capacity amongst a diverse group of professionals to engage in the stepped model of care aimed at responding to the cognitive support needs of cancer survivors. Furthermore, the

self-help resources will facilitate individuals affected by cancer to self manage their cognitive functioning. Several steps towards sustainability and sharing of learning have therefore been undertaken as a result of this pilot project. The willingness and renewed confidence witnessed amongst staff groups to contribute to this aspect of care, coupled with cancer survivors' demands for integrated care of their whole wellbeing will be the ultimate drivers for change.

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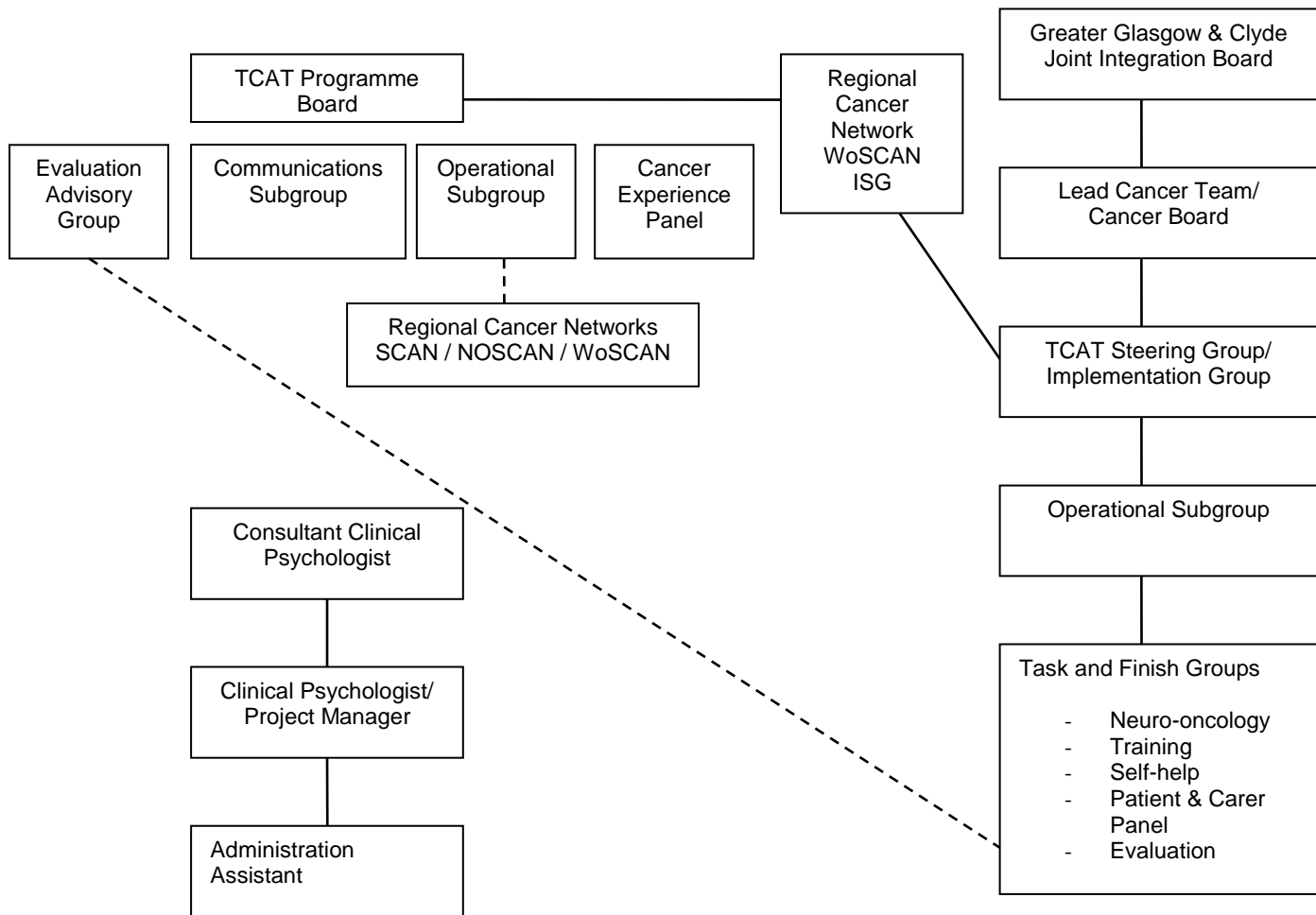
## APPENDIX 1 – STEERING GROUP MEMBERSHIP

### NHS Greater Glasgow and Clyde Phase 2: TCAT Project Steering Group

No.	Name	Position	Partner Organisation
1	Chris Hewitt	Consultant Clinical Psychologist (Chair)	NHS Greater Glasgow and Clyde
2	Natalie Rooney	Deputy Chair, Project Lead, Macmillan Principal Clinical Psychologist	NHS Greater Glasgow and Clyde
3	Gary Jenkins	Clinical Director, Oncology Service	NHS Greater Glasgow and Clyde
5	Elaine Hamilton/Claire Alexander	Associate Macmillan Development Manager/ Partnership Quality Lead for West of Scotland	Macmillan Cancer Support
6	Jane Beresford/ Jane Grant	Health Improvement Lead – Life Circumstances	NHS Greater Glasgow and Clyde
7	Craig Broadfoot	Clinical Service Manager (Beatson)	NHS Greater Glasgow and Clyde
8	Jill Carson	Adult Services Manager, NW Sector	Glasgow City Council
9	Carol Cochrane	Support Specialist	Brainstrust
10	Helen Bulbeck	Director of Services and Policy	Brainstrust
11	Gus Ironside	Operations Manager	Brain Tumour Charity
12	Jonathan Pearce	Manager	Lymphoma Association
13	Debbie Roebuck	Counselling Psychologist	Maggie’s Centre, Glasgow
14	Madaline Alexander	Manager	Cancer Support Scotland
15	Ken O’Neill	Primary Care: Lead Cancer GP	NHS Greater Glasgow and Clyde
17	Margaret Welsh	Network Service Manager Regional TCAT Project Lead	West of Scotland Cancer Network
18	Sandra White	Regional TCAT Clinical Lead	West of Scotland Cancer Network
19	Diana Johnston Catriona Gorton	Lay Representatives, Cancer Experience Panel	Cancer Experience Panel

No.	Name	Position	Partner Organisation
20	David McLackland	Patient Representative	Member of Regional ISG
21	Fiona Whyte	Senior Learning and Development Manager	Macmillan Cancer Support
22	Donna McLeod	Vocational Rehabilitation Project	Macmillan Cancer Support
23	Sandra McDermott	Improving Cancer Journey Programme Manager	Glasgow City Council/Macmillan
24	Mairi Mackinnon	CNS, Neuro-Oncology	NHS Greater Glasgow and Clyde
25	Maureen Thomson	Consultant Radiographer	NHS Greater Glasgow and Clyde
26	Lorraine Webster	Information and Support Radiographer and Counsellor	NHS Greater Glasgow and Clyde
27	Elaine Ross	Macmillan CNS, Head and Neck Cancer	NHS Greater Glasgow and Clyde
28	Sarah Wilson	CNS, Head and Neck Cancer	NHS Greater Glasgow and Clyde
29	Carol Stevenson	Senior Nurse, Chemotherapy Day Unit	NHS Greater Glasgow and Clyde
30	Laura Meehan	Senior Nurse, Haemato-Oncology	NHS Greater Glasgow and Clyde
31	Jeff White	Consultant Oncologist	NHS Greater Glasgow and Clyde
32	Nicola Goudie/ Lorraine Crothers	Clinical Neuropsychologist/ Specialist Occupational Therapist	NHS Greater Glasgow and Clyde
33	Pauline McIlroy	Advanced CNS, Breast Cancer	NHS Greater Glasgow and Clyde
34	Heather Wotherspoon	MCN Manager	West of Scotland Cancer Network
35	Bill Clark	Social Care Advisor	Macmillan Cancer Support
36	Louise Bryan/ Victoria Grant	Admin Support/ Assistant Psychologist	NHS Greater Glasgow and Clyde

## APPENDIX II – PROJECT REPORTING STRUCTURES



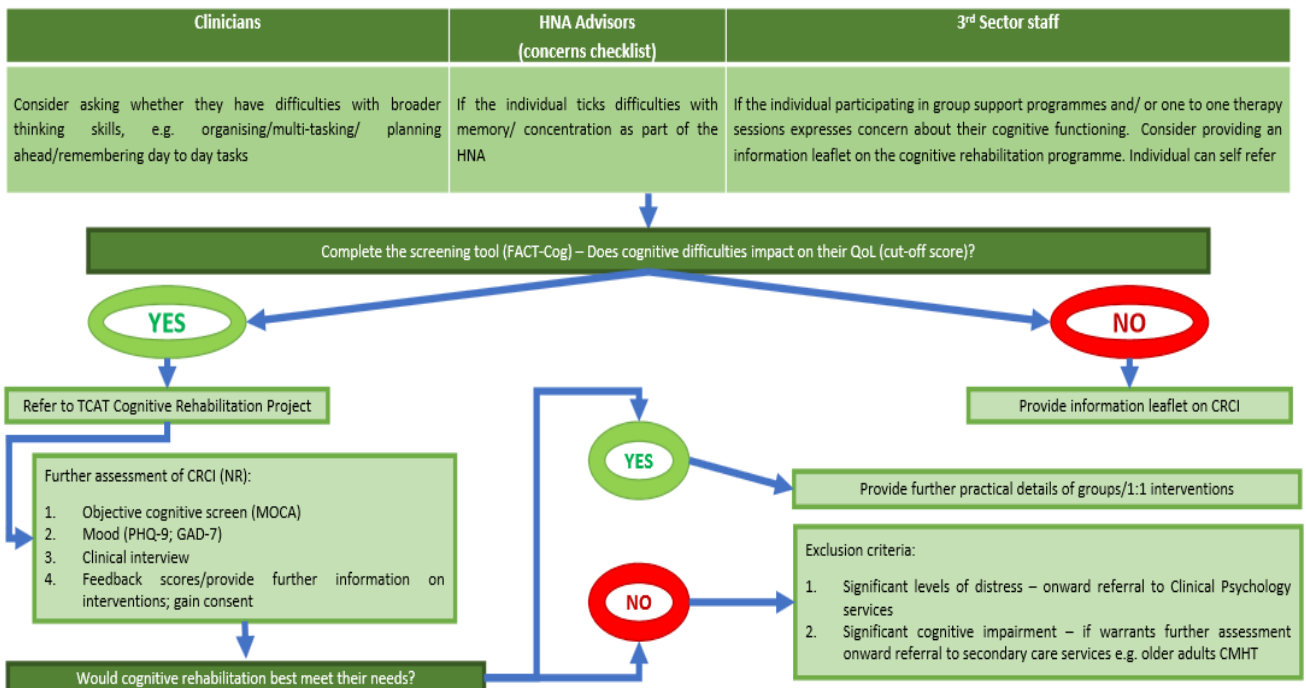


# APPENDIX III – PROJECT DOCUMENTATION

## Referral Pathway

# TCAT Cognitive Rehabilitation Support Programme

### Identifying Cognitive Problems:





TRANSFORMING  
YOUR  
CANCER CARE

WE ARE  
MACMILLAN.  
CANCER SUPPORT

NHS  
SCOTLAND

## Cancer-related Cognitive Impairment

### New Cognitive Rehabilitation & Support Programme - Information for Referrers

Macmillan Cancer Support is funding a national programme to develop services in acute services, primary care and the voluntary sector to support patients following completion of their cancer treatment - the Transforming Care after Treatment (TCAT) programme. Dr Chris Hewitt, Consultant Clinical Psychologist at the Beatson West of Scotland Cancer Centre secured two year funding under TCAT to develop a cognitive rehabilitation and support programme for patients presenting with cognitive difficulties secondary to their cancer treatment.

Cancer-related cognitive impairment (CRCI) refers to a range of cognitive deficits which are frequently reported by patients with cancer, including difficulties with memory, attention, concentration and executive functioning (i.e. planning, organisation and problem solving). Patients often comment about the wide-ranging impact of cognitive difficulties, affecting home life and relationships as well as employment. The nature of these difficulties can have a significant impact on an individual's ability to live as independently as they would want due to challenges such as organising/adhering to medications, remembering appointments, organising shopping and preparing meals, enjoying recreation activities due to impaired concentration, managing successful return to work etc.

The cognitive rehabilitation and support programme consists of group and individual sessions for patients and carers/ family members are invited to join in on the last session. In addition, self-help materials (information leaflets; DVDs) will be developed. It is expected that the majority of patients will be experiencing mild to moderate degrees of impairment and their needs would be best met by these information resources.

For those presenting with more significant cognitive difficulties they may benefit from participating in cognitive rehabilitation sessions facilitated by a Clinical Psychologist. Under the TCAT programme, patients can participate in a five-week course which provides information on memory; attention; problem-solving and ways of managing these changes in thinking processes. These will be group sessions with the added value of providing informal peer support. Carers are invited to attend the last session of the course which entails information about cancer-related cognitive impairment; ways of supporting their family members as well as addressing their own support needs. For patients who would prefer receiving these interventions on an individual basis there are a limited number of sessions available.

If you think that these cognitive rehabilitation interventions may be of benefit to your patients, we would welcome your referral to this service. The Clinical Psychologist will arrange an initial appointment to discuss with the patient what is involved in the interventions as well as to complete brief cognitive screens and mood measures. You will receive a summary of their engagement with the group programme.

The group cognitive rehabilitation sessions will take place in the Glasgow City Council libraries and local community hospitals. These interventions are open to all patients across the WoSCAN region who are able/ willing to travel to Glasgow.

Please either send a completed referral form or the patient's name and CHI number to Natalie Rooney.

Dr Natalie Rooney  
Macmillan Principal Clinical Psychologist  
Email: [natalie.rooney@ggc.scot.nhs.uk](mailto:natalie.rooney@ggc.scot.nhs.uk)  
Project email: [tcats@ggc.scot.nhs.uk](mailto:tcats@ggc.scot.nhs.uk)

Tel: 0141 201 0124  
Mobile: 07970 372919

Please do not hesitate to email or phone Natalie to find out more about the programme.

If you wish to post your referral form, please send to:

Dr Chris Hewitt  
Consultant Clinical Psychologist  
Psychology Office - Level 1  
Beatson West of Scotland Cancer Centre  
1053 Great Western Road  
Glasgow  
G12 0YN

## **Patient Information Leaflet**

### **Who we are?**

If you are undergoing cancer treatments or have completed treatment and are experiencing difficulties with your memory or concentration, then we can help. For example, you may have noticed that you can forget dates, phone numbers or names that you would normally remember or struggle to follow the thread of a conversation or can take longer to complete daily tasks.

Macmillan Cancer Support has funded a project to look at how we can best support people who have noticed these changes in their memory, concentration or ability to plan/organise things.

### **How we can help?**

We can provide support that will consist of group sessions looking at what memory and attention is and how you can work around these difficulties. The group sessions will take place in the Glasgow City Council libraries. The group means you will have the chance to share your experience with other people who are having the same problems. If a group setting doesn't suit then we can look at individual sessions for you.

### **Programme content**

**Week 1: How does cancer treatment affect my memory?**

**Week 2: Attention – what is it? How can I improve it?**

Looking at sustained attention; selective attention; alternating attention; divided attention.  
Tips on how improve it.

**Week 3: Memory – what is it? How can I improve it?**

Looking at short-term memory and what is involved in putting things to memory. Tips on how to improve it.

**Week 4: Planning and Problem Solving – what is it? How can I improve it?**

Looking at multi-tasking and goal setting. Tips on how to improve these skills.

**Week 5: Tying it together!**

Summarising the various cognitive compensation strategies and discussing how other factors e.g. fatigue and emotions play a part in managing day to day memory.

You are invited to bring along a family member/ friend to this session so that they are aware of these common memory difficulties. There will be time for discussion on ideas of how best to adapt to these memory changes throughout and after your treatment.

### **What will happen?**

If you are experiencing problems with your memory since starting your cancer treatment, you should discuss this with your health professional. In turn they will ask you to fill in a short questionnaire about your memory. Following this, they can refer you for the kind of support sessions detailed above

You may also self-refer. Simply contact the team and they can tell you more about the programme.

The Clinical Psychologist will meet with you to tell you more about what is involved in the sessions. If this is something you would benefit from, they will provide you with information about where and when the sessions will take place.

### **Contact us**

**To find out more how we can provide support, please contact us:**

**Transforming Care after Treatment (TCAT) Cognitive Rehabilitation and Support**

Department of Clinical Psychology  
2<sup>nd</sup> Floor  
West Glasgow ACH  
Dalnair Street  
Glasgow, G3 8SJ

Email: [tcata@ggc.scot.nhs.uk](mailto:tcata@ggc.scot.nhs.uk)  
Tel: 0141-301-7792

## APPENDIX IV – OUTCOME MEASURES

### FACT-Cognitive Function (Version 3)

Below is a list of statements that other people with your condition have said are important. Please circle or mark one number per line to indicate your response as it applies to the past 7 days.

		Never	About once a week	Two to three times a week	Nearly every day	Several times a day
<b><u>PERCEIVED COGNITIVE IMPAIRMENTS</u></b>						
CogA1	I have had trouble forming thoughts .....	0	1	2	3	4
CogA3	My thinking has been slow.....	0	1	2	3	4
CogC7	I have had trouble concentrating .....	0	1	2	3	4
CogM9	I have had trouble finding my way to a familiar place.....	0	1	2	3	4
CogM10	I have had trouble remembering where I put things, like my keys or my wallet .....	0	1	2	3	4
CogM12	I have had trouble remembering new information, like phone numbers or simple instructions .....	0	1	2	3	4
CogV13	I have had trouble recalling the name of an object while talking to someone .....	0	1	2	3	4
CogV15	I have had trouble finding the right word(s) to express myself.....	0	1	2	3	4
CogV16	I have used the wrong word when I referred to an object .....	0	1	2	3	4
CogV17b	I have had trouble saying what I mean in conversations with others .....	0	1	2	3	4
CogF19	I have walked into a room and forgotten what I meant to get or do there.....	0	1	2	3	4
CogF23	I have had to work really hard to pay attention or I would make a mistake .....	0	1	2	3	4
CogF24	I have forgotten names of people soon after being introduced.....	0	1	2	3	4

### FACT-Cog (Version 3)

Please circle or mark one number per line to indicate your response as it applies to the past 7 days.

		Never	About once a week	Two to three times a week	Nearly every day	Several times a day
CogP25	My reactions in everyday situations have been slow.....	0	1	2	3	4
CogC31	I have had to work harder than usual to keep track of what I was doing .....	0	1	2	3	4
CogC32	My thinking has been slower than usual .....	0	1	2	3	4
CogC33a	I have had to work harder than usual to express myself clearly .....	0	1	2	3	4
CogC33c	I have had to use written lists more often than usual so I would not forget things .....	0	1	2	3	4
CogMT1	I have trouble keeping track of what I am doing if I am interrupted.....	0	1	2	3	4
CogMT2	I have trouble shifting back and forth between different activities that require thinking .....	0	1	2	3	4

Please circle or mark one number per line to indicate your response as it applies to the past 7 days.

		Never	About once a week	Two to three times a week	Nearly every day	Several times a day
<b><u>COMMENTS FROM OTHERS</u></b>						
CogO1	Other people have told me I seemed to have trouble <u>remembering information</u> .....	0	1	2	3	4
CogO2	Other people have told me I seemed to have trouble <u>speaking clearly</u> .....	0	1	2	3	4
CogO3	Other people have told me I seemed to have trouble <u>thinking clearly</u> .....	0	1	2	3	4
CogO4	Other people have told me I seemed <u>confused</u> .....	0	1	2	3	4

### FACT-Cog (Version 3)

Please circle or mark one number per line to indicate your response as it applies to the past 7 days.

		Not at all	A little bit	Some-what	Quite a bit	Very much
<b><u>PERCEIVED COGNITIVE ABILITIES</u></b>						
Cog PC1	I have been able to concentrate .....	0	1	2	3	4
Cog PV1	I have been able to bring to mind words that I wanted to use while talking to someone .....	0	1	2	3	4
Cog PM1	I have been able to remember things, like where I left my keys or wallet .....	0	1	2	3	4
Cog PM2	I have been able to remember to do things, like take medicine or buy something I needed.....	0	1	2	3	4
Cog PF1	I am able to pay attention and keep track of what I am doing without extra effort.....	0	1	2	3	4
Cog PCH 1	My mind is as sharp as it has always been.....	0	1	2	3	4
Cog PCH 2	My memory is as good as it has always been .....	0	1	2	3	4
Cog PMT 1	I am able to shift back and forth between two activities that require thinking .....	0	1	2	3	4
Cog PMT 2	I am able to keep track of what I am doing, even if I am interrupted .....	0	1	2	3	4

Please circle or mark one number per line to indicate your response as it applies to the past 7 days.

		Not at all	A little bit	Some-what	Quite a bit	Very much
<b><u>IMPACT ON QUALITY OF LIFE</u></b>						
CogQ35	I have been upset about these problems.....	0	1	2	3	4
CogQ37	These problems have interfered with my ability to work .....	0	1	2	3	4
CogQ38	These problems have interfered with my ability to do things I enjoy.....	0	1	2	3	4
CogQ41	These problems have interfered with the quality of my life .....	0	1	2	3	4

### Generalized Anxiety Disorder 7-item (GAD-7) scale

Over the last 2 weeks, how often have you been bothered by the following problems?	Not at all sure	Several days	Over half the days	Nearly every day
1. Feeling nervous, anxious, or on edge	0	1	2	3
2. Not being able to stop or control worrying	0	1	2	3
3. Worrying too much about different things	0	1	2	3
4. Trouble relaxing	0	1	2	3
5. Being so restless that it's hard to sit still	0	1	2	3
6. Becoming easily annoyed or irritable	0	1	2	3
7. Feeling afraid as if something awful might happen	0	1	2	3
<i>Add the score for each column</i>	+	+	+	
Total Score ( <i>add your column scores</i> ) =				

If you checked off any problems, how difficult have these made it for you to do your work, take care of things at home, or get along with other people?

- Not difficult at all \_\_\_\_\_
- Somewhat difficult \_\_\_\_\_
- Very difficult \_\_\_\_\_
- Extremely difficult \_\_\_\_\_

Source: Spitzer RL, Kroenke K, Williams JBW, Lowe B. A brief measure for assessing generalized anxiety disorder. *Arch Intern Med.* 2006;166:1092-1097.



## PATIENT HEALTH QUESTIONNAIRE (PHQ-9)

NAME: \_\_\_\_\_ DATE: \_\_\_\_\_

Over the last 2 weeks, how often have you been bothered by any of the following problems?  
(use "✓" to indicate your answer)

	Not at all	Several days	More than half the days	Nearly every day
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed, or hopeless	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much	0	1	2	3
4. Feeling tired or having little energy	0	1	2	3
5. Poor appetite or overeating	0	1	2	3
6. Feeling bad about yourself—or that you are a failure or have let yourself or your family down	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed. Or the opposite — being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3
9. Thoughts that you would be better off dead, or of hurting yourself	0	1	2	3

add columns  +  +

(Healthcare professional: For interpretation of TOTAL, please refer to accompanying scoring card). TOTAL:

10. If you checked off any problems, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people?	Not difficult at all	_____
	Somewhat difficult	_____
	Very difficult	_____
	Extremely difficult	_____

# Cognitive Rehabilitation and Support Following Cancer Treatment

Authors: Victoria Grant, Natalie Rooney, Christopher Hewitt



[tcat@ggc.scot.nhs.uk](mailto:tcat@ggc.scot.nhs.uk)

Transforming care after treatment

## The Need

35% of cancer patients will experience *Cancer Related Cognitive Impairment (CRCI)*.

*CRCI* refers to a range of cognitive deficits including difficulties with memory, attention, concentration and executive functioning (i.e. planning, organisation and problem solving).

*CRCI* is potentially long term, affecting home-life, relationships and employment; impacting significantly on quality of life, self-confidence and independence. Due to challenges adhering to medications, remembering appointments, preparing meals, enjoying recreation activities and managing successful return to work, these difficulties can have a significant impact on people's ability to live as independently as they would want.

## Addressing the Need

A group-based intervention was delivered to patients with complex *CRCI*. Embedded in communities and delivered across a range of hospital and community settings, the groups supported self-management of symptoms through psycho-education and evidence based cognitive compensatory strategies. The group atmosphere also enabled peer and professional support and validation.

Referrals were welcomed from across health and third sector organisations, with appropriate signposting provided to ensure continuous support from diagnosis to several years post treatment.

We used feedback from patients and carers to adapt and improve the content of our groups and self-help literature, inviting patients to use their own voices through public videos and talks at conferences.

## Positive Impact

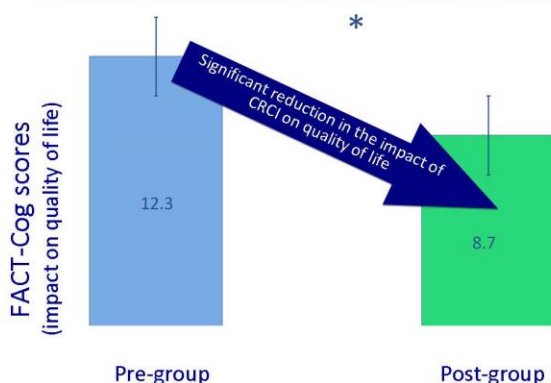
We asked the fifty nine individuals (who have attended the programme to date) how much their *CRCI* impacts their quality of life.

The mean scores from before and after attending the group are shown below (i).

Results showed that by attending the group, the effect that *CRCI* had on participants' quality of life, was significantly reduced. The measure used was the *Functional and Cognitive Assessment of Cancer Therapy- Cognitive Function Version 3 (FACT-Cog)*.

Qualitative feedback about the benefits was also collected, represented below (ii), where size of word correlates with frequency within the feedback.

### i) Group Effect on *CRCI* Impacted Quality of Life



### ii) Qualitative feedback from group



Myers JS. Cancer and chemotherapy-related cognitive changes: The patient experience. In Seminars in oncology nursing 2013 Nov 30 (Vol. 29, No. 4, pp. 300-307). WB Saunders  
Jandins MC, Kelder SP, Allen TA, Morrow GR. Prevalence, mechanisms, and management of cancer-related cognitive impairment. International Review of Psychiatry. 2014 Feb 1;26(1):102-13

## APPENDIX VI – PROJECT CONFERENCE PROGRAMME



TRANSFORMING  
YOUR  
CANCER CARE

WE ARE  
MACMILLAN.  
CANCER SUPPORT

NH  
SCOTLAND

Memory and concentration changes after cancer treatment. What do we know? What can help?

**Monday 24<sup>th</sup> April**

9:30am – 3:00pm

Glasgow Pond Hotel

Great Western Rd, Glasgow G12 0XP

Plenary speaker: Professor Robert Ferguson, University of Pittsburgh, School of Medicine. Prof Ferguson has conducted clinical trials investigating cancer-related cognitive changes and will give two talks at the conference sharing his research in this area as well as clinical interventions which support individuals adjusting to cancer-related cognitive changes.

The cognitive rehabilitation group programme which aims to support individuals with memory and concentration changes following cancer treatment has been running for a year under the Transforming Care after Treatment (TCAT) programme. We are keen to raise awareness of this issue and share information on what can help.

### Programme Content

9:30 – 10:00am: Registration and coffee

10:00 – 10:10am: Opening of conference – Gary Jenkins, Director: Regional Services Directorate, NHS Greater Glasgow & Clyde

10:10 – 11:00am: ***Cancer-related cognitive change – what it is and what we know*** - Professor Robert Ferguson, University of Pittsburgh

11:00 – 11:10am: ***Patient experience*** – Andrea Joyce

11:10 – 11:30am: ***TCAT Cognitive Rehabilitation project*** - Dr Chris Hewitt, Consultant Clinical Psychologist, BWoSCC

11:30 – 11:50am: **BREAK**

11:50 – 12:30: Round table discussions: looking at how we can incorporate lessons learned from the project within existing practice

12:30 – 13:15: **LUNCH**

13.15 -13.30: Feedback from round table discussions

13:30 – 14:15: ***Memory and Attention Adaptation Training (MAAT): What can help in managing cancer-related cognitive changes.*** Professor Robert Ferguson

14:15 – 14:45: ***Where now?*** What do service users wish to see provided within health services to support them with adapting to cognitive changes post treatment?

14:45 – 14:55: ***The role of the Cancer Experience Panel within the TCAT programme***– Diana Johnston

Closing remarks – Dr Chris Hewitt, Consultant Clinical Psychologist, BWoSC

## APPENDIX VII – CRCC PATIENT INFORMATION BOOKLET



Information on

# **Cancer-related Cognitive Changes (CRCC)?**





## **What are Cancer-related Cognitive Changes (CRCC)?**

After cancer treatment some people notice changes in their concentration and the way they think. Women with breast cancer were the first to report these problems which they linked to their chemotherapy treatment. They called these changes 'chemobrain' or 'chemofog' but it is not clear what causes these changes, so calling them 'chemobrain' may not be accurate. Following radiotherapy treatment, throughout and after hormonal treatment, people can also experience these attention and memory changes. Cancer-related cognitive changes (CRCC) and mild cognitive impairment are other terms used, but cognitive simply means thinking. Most people who have cognitive changes are able to do everyday things but they may notice they aren't as able to do some things quite as well as they did before they had cancer. The changes are often mild and subtle. They aren't progressive and do improve over time. But if you do have them, they can affect your everyday life and this can be quite frightening for some people.

## **What causes CRCC?**

It is not known for certain why these symptoms happen and why they happen in some people but not in others. Doctors and other researchers believe that several factors are likely involved in causing the symptoms of cancer-related cognitive changes, including:

- the cancer itself
- cancer treatments, such as chemotherapy, radiotherapy and antibody treatments (especially if you have more intensive treatments such as high-dose chemotherapy and a stem cell transplant)
- side effects of cancer treatments,
- hormone changes caused by cancer treatments, such as an early menopause.

Researchers recently used fMRI scans to look into whether the brain works differently for people who have had cancer treatments. One study carried out by Professor Ferguson and colleagues

involved identical twins; one who was treated for breast cancer which included surgery and chemotherapy and the other who did not have breast cancer. The sisters completed a series of memory tests whilst their brains were being scanned.

The tests involved paying attention, remembering information and having a good reaction time. Although their actual performance was the same, the twin with chemotherapy had a lot more activity in her brain. This extra brain activity suggests that the brain has to work a lot harder to complete these tasks which previously they would have carried out with ease.

The Cancer Research UK website ([www.cancerresearchuk.org](http://www.cancerresearchuk.org)) has useful information about cancer-related cognitive changes and current research into the condition.

## How might I be affected?

Knowing more about these memory and concentration changes can be helpful in managing them. The changes can come and go but how much you notice them seems to depend on what you are doing. These changes can be frustrating and can affect how you feel. Experiencing CRCC can impact on your home and work life.



*"It got to the stage where I stopped meeting up with friends because I couldn't keep up with the conversation. I couldn't remember and the subject had changed, I still was on the previous subject. Somebody would say something and my mind went a total blank, I had no idea what they were talking about and yet I had been involved, what I thought was involved, in the conversation."*  
(Jess, Breast Cancer Patient)

### **The type of difficulties you may notice are:**

- Your memory – forgetting dates, phone numbers or names that you would normally remember
- Concentrating on tasks or on your work – even on simple things like preparing a meal
- Thought processes that you normally find easy – such as making shopping lists, doing puzzles or adding up numbers in your head
- Multi-tasking – doing more than one task at a time
- Finding the right words for things
- Following the thread of a conversation
- Making plans
- Learning new facts – you might get confused easily or take longer to learn things.

### **Coping with CRCC**

Individuals' stories highlight that these memory changes are often invisible to other people. One of the main challenges after finishing treatment is that everyone expects you to be back to normal, but it might not be that easy. People around you are willing you on but you might not be ready as adjusting emotionally takes time. There are many practical tips which can help in managing these memory and concentration changes.

There are general coping strategies which can improve our general wellbeing and in turn can help our thinking and concentration.

*"I was using reminders...and for me, everything pointed to slowing down and regaining my confidence. " (Dougie, Prostate Cancer Patient)*



## **Manage fatigue or tiredness:**

- ✓ **Take breaks**
  - Fatigue can make attention more difficult.
  - Work for short periods of time, planning breaks into your day.
- ✓ **Work at your best time of day**
  - Are you a morning/afternoon/evening person?
  - Complete your most difficult tasks when you have the most energy.
- ✓ **Start a bedtime routine**
  - If sleep is a problem, start to develop a routine before bed, preparing your body for sleep, and making it more likely you'll get a good night's sleep.
- ✓ **Limit caffeine**
  - If you're particularly sensitive to caffeine, avoid it any time after noon.
  - This will help you get a better night's sleep if caffeine is a factor.



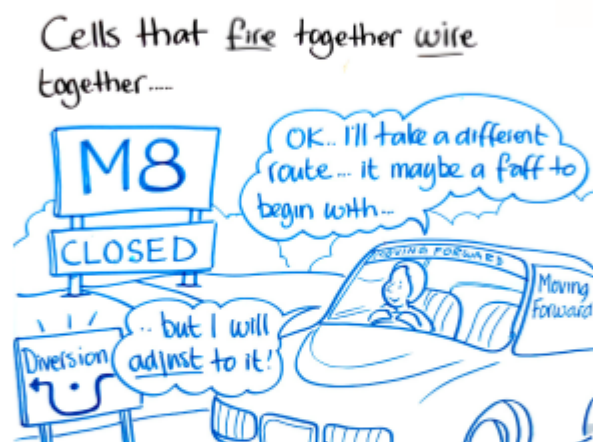
### Look after yourself:

- ✓ Don't stress(!)
  - Easier said than done! We know problems with attention and memory can cause stress, but stress can make this worse!
  - What works for you? (*exercise, talking to friends, mindfulness, a bath etc.*)
  - For ideas on what could help you, visit: [www.stepsforstress.org](http://www.stepsforstress.org)
- ✓ Let others help
  - Often others will want to help. If they do, explain what you find difficult and how you'd like them to help.
- ✓ Notice how you feel
  - Attention and memory problems can cause anxiety and low mood, and often our emotions can sometimes get on top of us. Unfortunately these emotions can make attention and memory worse, and become a vicious cycle. Like with stress, do what works for you to process your emotions, but if you notice that you can no longer manage your emotions, it may help to speak to your GP about what can help.



## Cognitive Coping Strategies

The other type of coping strategies involves doing things in a different way to help “compensate” or work around the changes to attention and memory. This can be referred to as cognitive rehabilitation. For example, this might involve using a diary, or using visual images to remember. You could think of using cognitive coping strategies as being similar to using a road diversion. Over time, this new route will become easier and still gets you to your destination!



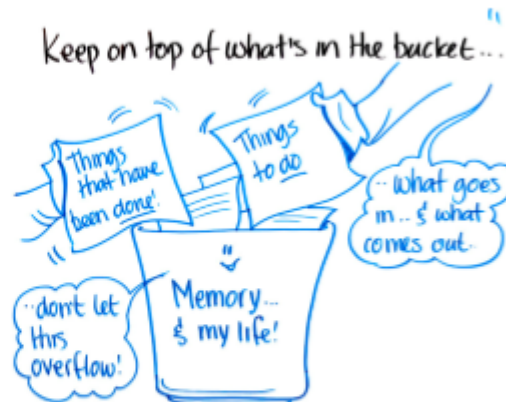
The following cognitive coping strategies have been divided into attention; memory; executive function (planning and organisational skills) and are based on this cognitive rehabilitation approach which serves to put into place various ways of working around the memory and concentration changes.

*"I used to have one pad and pen and if I remembered something, I'd put it down, mark it down. But I'd be up the stairs and by the time I got down the stairs trying to remember something, I'd have forgotten it. So, what I did was put a pad and pen in every room and that meant I had five notepads; I'd collate them all at the end of the week and I had my shopping list."*  
(Jess, Breast Cancer Patient)

## Attention:

Attention is the basis for learning and memory; you must first pay attention to something before you can put it to memory. It is a limited resource. We can think of it as a bucket that can only hold so much. When it's full it can overflow, meaning we can't pay attention to things or remember them in the future.

It can be filled up by many different things such as; noisy environment, fatigue, physical ill-health, medication, and stress/ anxiety, making it hard to pay attention.



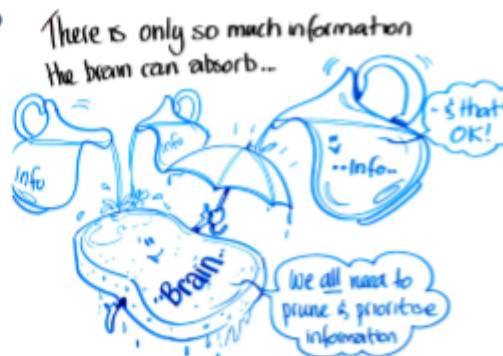
## How to improve your attention:

### Set up the right conditions:

- ✓ Try to remove distractions
  - (e.g. by turning of the tv/radio if someone is talking to you)
  - A quiet, calm atmosphere will help.
- ✓ Focus on one thing at a time.
  - Don't try to take in too much information at once.
- ✓ Make a plan
  - Apply structure or break tasks down into smaller pieces. This makes it easier to get back on track if you get distracted.
- ✓ Keep a notepad handy
  - (e.g. by the telephone, in your bag or pocket)
  - Jot things down. The more you use it, the less you're likely to need it.

## Memory:

Memory relies on many stages to work effectively, attention being one of them. We can think of it as a filing cabinet. Memories must be filed correctly in order to find at a later date. Similar to our attention capacity, there are many factors which can affect this process of filing and finding memories.



## How to improve your memory:

### Changes to your home:

- ✓ A place for everything, and everything in its place
  - This can help for keys, wallet etc. It'll mean that a habit is soon formed and you don't rely on memory. It can also help others to help you.
- ✓ Remind yourself
  - Using a whiteboard/chalkboard/corkboard in your home can do this for you,
  - Try adding appointments for the week, shopping lists or things to do.
  - Get in the habit of glancing at it every time you enter and leave the room.
- ✓ It's okay to rely on tools
  - Diaries, calendars or notebooks (either paper or electronic) can help keep all important information in one place.
  - Like with the chalkboard, try to check these regularly. Mobile phones have plenty of apps that are designed for reminding you of tasks or lists. See what works for you.
- ✓ Keep a notepad handy
  - (e.g. by the telephone, in your bag or pocket)
  - Jot things down. The more you use it, the less you're likely to need it.

## When learning new information:

- ✓ Make it as easy as possible
  - Try to get rid of distractions such as tv or radio.
  - Take your time and write it down.
  - Repetition helps learning, repeat the information as much as possible.
- ✓ Tricks and strategies
  - Rhymes, rules or stories can help our memory.
  - Making associations with something meaningful or forming visual images helps

## Executive function (planning and organisational skills):

Executive function is one of the most complex aspects of our thinking. We can think of it as the chief executive or even the conductor of our brain. He plans, organises, adapts, directs, weighs up decisions and decides what the priorities are. The factors which affect our attention and memory also can impact on our executive function.





## **How to improve your executive function:**

### **Staying organised:**

- ✓ A step-by-step approach
  - Relying on visual organisational aids can help our thinking and planning
- ✓ It's okay to rely on tools
  - Organisers, computers or phones with alarms can help keep you on track,
- ✓ Ask for written directions with spoken instructions where possible
  - Like with the chalkboard, try to check these regularly. Mobile phones have plenty of apps that are designed for reminding you of tasks or lists. See what works for you.
- ✓ Keep a notepad handy
  - (*e.g. by the telephone, in your bag or pocket*)
  - Jot things down makes it easier to stay organised.

### **Managing your time and space:**

- ✓ Lists, lists, lists
  - Make checklists and to-do lists and estimate how long tasks will take.
  - This will help you prepare and prioritise, and make planning easier.
- ✓ Breaking tasks down
  - Large activities can be broken into parts to make them more achievable.
- ✓ Tidy space, tidy mind
  - Minimising clutter and working in an organising space will really help you think.
  - Scheduling a weekly time to clean and organise will help keep on top of this
- ✓ Reduce distractions
  - Try to get rid of noises around you such as tv or radio.

## Getting help and support

The adjustment to the emotional and mental side of things after treatment is also invisible to others. They may not understand that you're feeling more emotional or see the struggles with your concentration. The more people that know more about these memory and concentration changes, the more they will understand and the easier it will be for you to adjust and to do this in your own time.



## Support returning to employment



If you are returning to work, talk to your employer and occupational health department about how you are feeling so that they are aware of any potential difficulties you might have when you are back.

Ensuring that employers provide sufficient

accommodations for people with "invisible conditions" is a government priority. There are several agencies which provide information and advice on workplace health and wellbeing. Please see below for contact details of these agencies.

Invisible conditions include physical or mental difficulties which have a substantial and long-term adverse effect on an individual's ability to carry out day to day activities. The employment specific support agencies can guide you through what you are entitled to in order for you to carry out your job.



These support services also includes advocating on your behalf so that employers can meet their obligations under the Equality Act.

The Equality Act requires employers to take into consideration the impact of a condition on the employee's ability to carry out their role and to adjust the role to accommodate for this. The legal term for this is 'reasonable adjustments'.

In the case of cognitive changes examples of adjustments that may be considered to be reasonable are as follows:-

- Giving you longer to complete tasks
- Temporarily giving some of your work to a colleague
- Giving you extra breaks if you feel tired
- Flexible working arrangements
- Allocating a buddy or mentor to provide support
- Allowing you to have a phased return to work following a period of absence
- Giving time off to attend support groups, counselling or for psychological treatment such as cognitive behaviour therapy (CBT)
- Monitoring how you are coping with work including workload
- Providing written instead of verbal instructions



### **Employment-specific support agencies:**

There are several national agencies which provide free, impartial and professional work-related advice and support for people with long term conditions.

#### **Scottish Centre for Healthy Working Lives**

**Advice line: 0800 019 2211**

The Advice line offers immediate, free and confidential help and information on any matter concerning health and wellbeing in the workplace, including health and safety, occupational health and health promotion.

**Website: [www.healthyworkinglives.com](http://www.healthyworkinglives.com)**

#### **Fit for Work Scotland**

**Advice Line: 0800 019 2211**

Fit for Work Scotland is a free advice and assessment service supporting employees, employers and GPs to manage a return to work.

**Website: [fitforworkscotland.scot](http://fitforworkscotland.scot)**

### **Access to Work**

If the help you need at work is not covered by your employer making reasonable adjustments, you may be able to get help from Access to Work.

You need to have a paid job, or be about to start or return to one. You'll be offered support based on your needs, which may include a grant to help cover the costs of practical support in the workplace.

An Access to Work grant can pay for:

- special equipment, adaptations or support worker services to help you do things like answer the phone or go to meetings;
- help getting to and from work

You might not get a grant if you already get certain benefits.

The money does not have to be paid back and will not affect your other benefits.

Check: <https://www.gov.uk/access-to-work> for further information

## Acknowledgements

With thanks to Dr Natalie Rooney, Macmillan Principal Clinical Psychologist and Victoria Grant, Assistant Psychologist, Department of Clinical Health Psychology, West Glasgow ACH and to Diana Johnston, Cancer Experience Panel (CEP) representative for compiling this information.

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