



**why...**

**we hear you**

Providing emotional support to patients, families, friends and carers who have been touched by cancer or any other life threatening conditions.

**Delivering an  
adult cancer  
counselling  
service - an  
evaluation  
report 2017**

**When you ask **why...** we hear you.**

**we hear you**

**01373 455 255 [wehearyou.org.uk](http://wehearyou.org.uk)**



# We Hear You

We Hear You provides emotional support through free professional counselling services to anyone who has been affected by cancer or other life threatening conditions. We support children, young people and adults across Bath and North East Somerset, Somerset and Wiltshire.

The data in this report was collected and analysed by Shannon Cuthbertson as part of her Msc Health Psychology degree at the University of Bath.

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Registered Charity Number: 1156001

Published date: April 2017

## Acknowledgements

We would like to thank all those that took the time to speak to our researcher about their experience of cancer and of using the We Hear You counselling service, without your input this report would not have been possible.

The Advisory Board for this project were instrumental in informing our research and supporting the team at We Hear You in the development of information that was sensitive to the needs of those using our service. This ensured that we set boundaries and to had rigorous processes in place should further support be required to those that participated.

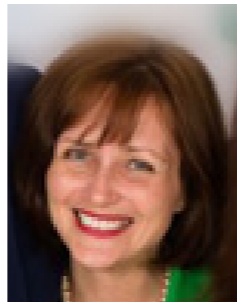


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Anne Montague,  
Chair



Melissa Hillier,  
Director

By the end of 2017 there will be more than 2.5 million people in the UK living with (and beyond) cancer. This figure is set to rise to 4 million by 2030.

There has never been a greater need for the emotional support that We Hear You provides and this report was commissioned to build on the evidence the charity already gathers to explore in greater detail the impact of the adult counselling service.

We Hear You provides the often-forgotten part of cancer care – supporting peoples' psychological needs by providing free professional counselling to anyone who has been touched by cancer or other life threatening conditions. The majority of our service is community based and we work closely with local providers and commissioners of healthcare to ensure that patients and families are aware of the support we can provide.

Our service is free and all our counsellors are highly experienced in dealing with all aspects and stages of cancer and life threatening conditions, including bereavement.

Whilst medical needs are dealt with extremely well by the NHS, patients and their families have told us that they often find the psychosocial aspects of cancer care to be unsupported. We Hear You was established to provide this much needed and vital support. We are the only charity in this area offering this service.

A key part of our support is for those around the patient, to ensure that emotional support is provided to carers, family members and friends. Over 40% of those that use our support are carers and we recognise that cancer not only affects the individuals but often has an impact on the whole family and beyond.

In the last two years the charity has seen an increase in referrals by nearly 60% and it is currently delivering over 90 counselling sessions a week. However, we know we are only scratching the surface of need and the increase in demand is ever growing.

With the implementation of the "Achieving World-Class Cancer Outcomes – A strategy for England 2015 – 2020" under way

and the ever-growing demand on cancer services the charity felt it was an appropriate time to undertake this ground-breaking research to help us to evaluate and communicate to all our key stakeholders the impact that the professional counselling we provide has.

It has been hugely powerful to reflect on the experiences of those that use the service and to see the impact we make on a daily basis, and we hope this report will be a catalyst in supporting our work and enable us to develop and grow.

Anne Montague, Chair

Melissa Hillier, Director

This report explores the experiences of some of the people who have used our service. It is based on a study carried out over the summer of 2016 and sets out key themes from this work along with outcomes and recommendations for future development.

We were particularly interested in understanding the participants' experience with us as they progressed with their counselling sessions. As over 90% of adults that use our service are affected by cancer we also wanted to understand how it impacted on individuals (and their families) lives and how counselling has had an impact on participants' experience of cancer.

This piece of work was designed to measure the impact and effectiveness of the adult counselling service we provide to help us formulate future service developments as well as to understand better the need for high quality cancer counselling.

This ground-breaking project is the first the charity has undertaken and marks the recognised need for measuring behavioural change in those we support.

The study conducted used a mixed model approach using two validated tools (MyCAW<sup>1</sup> and PHQ-9<sup>2</sup>) along with face-to-face interviews. Surveys were conducted pre and post counselling, along with an internally developed WHY...survey which was completed post counselling. 50 clients were eligible to take part, 24 people were contacted and six participants completed all stages of the research.

### A summary of the findings can be categorised into three over-arching themes

#### 1. Impact of cancer

This theme summarises the ways in which the participants were impacted by cancer. This explores the 'ripple effect' of cancer which stipulates how a cancer diagnosis affects the patient and their supporters in every aspect of their lives.

#### 2. Impact of counselling

This theme outlines the ways in which participants felt the counselling impacted on them and the management of their circumstances.

#### 3. Best practice and learning

This theme considers the beneficial features of the WHY counselling service which enabled participants to get the most out of their sessions as well as identifying development opportunities and areas of learning.

From these themes we have identified some key recommendations and learning action points for the charity to take forward.

### Impact of Cancer - Key Recommendations

1. WHY... to carry out further in-depth work to understand the psychological impact of cancer on the patients and carers the charity supports, to help the charity meet the needs of those accessing our support.
2. WHY... to review the Impact of different types of cancer on individuals accessing our service to understand the similarities and differences of emotional need
3. This work has shown how cancer impacts those surrounding the patient particularly vulnerable family members such as children and young people. The charity will review the impact of its children and young people's counselling service on those that use it and those that support and fund it.

### Impact of counselling - Key Recommendations

1. WHY... to carry out a study to capture and evaluate the longer-term impact of the WHY... counselling service. This report offers a "snapshot" of clients experience over the course of their counselling with the charity. It would be valuable to measure the longer-term impact of the support provided, which would help the charity measure its longer-term outcomes.
2. WHY... to review the impact that the provision of its counselling support can have on individuals ability to self-manage their condition, For example, return to work, as well as their other key interactions such as with healthcare professionals, social services, financial support.

Our learning and best practice has also been enhanced by our greater understanding of what is valued about the service we provide by those that use our support and areas where improved communications, for example, may help manage expectations. We have also identified areas for consideration in what tools and methods we use in evaluating and measuring our work.

Overall, this report demonstrates that the support that We Hear You provides enhances the capacity for patients and carers to manage their individual experience of cancer. It provides people with the space, time and tools to understand their feelings and to acknowledge them and enables people to adapt more. Of the clients we interviewed for this report, each commended our service as being of benefit to their ability to return to work, their ability to communicate with their family and their acceptance of their circumstances. There was also a trend towards an improvement in psychological wellbeing; such as reduced depression scores and improvements in extent to which concerns were bothering clients.

We acknowledge that our sample size is small, and more work is required to extend these findings within our service. We were pleased however, to see a general trend even within the survey data to improved outcomes and we hope to be able to build on this pilot study to gather further data and information from those that use our service.

# Chapter 1

## Introduction

### Overview

By the end of 2017, there will be more than 2.5 million people living with and beyond cancer in the UK and this figure is expected to rise to 4 million by 2030<sup>3</sup>. This equates to approximately 12,000 new diagnoses in the area We Hear You covers. Although diagnoses are increasing each year, survival rates are too. Whilst this is extremely positive, it also means there are more people living with the physical and psychosocial impacts of cancer which compromise quality of life<sup>4</sup>. Many patients experience poor psychological wellbeing, with 32% diagnosed with a psychological disorder<sup>5</sup>. Depression occurs at a rate twice that of the general population<sup>6</sup>. Therefore, it is important for those living with and

- \* **The incidence of new cancer across the area WHY... works in is approximately 12,000 per year.**
- \* **Cancer affects family, friends and supporters**
- \* **1.1 million informal caregivers in the UK caring for someone affected by cancer**
- \* **67% of caregivers experience poor psychological wellbeing – including depression**
- \* **Caregiver stress has been shown to contribute to poorer patient outcomes**
- \* **Supporting the psychological wellbeing of those affected by cancer may reduce use of healthcare services as well as enabling people to return to work more quickly**

beyond cancer to have access to integrative support: services providing psychosocial support as well as medical care<sup>7</sup>.

Importantly, at **We Hear You (WHY...)** we understand that cancer does not only have an impact on those with a diagnosis.

Cancer elicits a 'ripple effect' in how it affects family, friends and supporters too<sup>8</sup>. In particular, there are 1.1 million informal caregivers in the UK caring for a person with cancer who have been described as 'co-sufferers' alongside the patient<sup>9</sup>. Caregivers also report poor psychological wellbeing<sup>10</sup> with as many as 67% experiencing symptoms of depression<sup>11</sup>. In turn, this may have an adverse impact on the wellbeing of the patient through affecting their ability to fulfil caregiving duties<sup>12</sup>, ability to administer medication<sup>13</sup> and in how caregiver stress can increase patient anxiety in the long-term<sup>14</sup>. In addition, caregiver stress and anxiety has been shown to contribute to poorer patient adjustment to their cancer experience<sup>15</sup>.

The focus on holistic cancer care has never been so important. In particular, providing person-centred care is the foundation of the Independent Task Force report (2015)<sup>16</sup> which stipulated the need for psychosocial support to be integrated into standard cancer care. Following this report, the NHS outlined

several recommendations to meet the objectives of the Five Year Forward View Cancer Strategy (2016)<sup>17</sup> by providing effective cancer care for all those affected across England. These recommendations emphasise how those affected by cancer should be supported with self-management of their circumstances, and should receive psychosocial support from community-based organisations. Supporting the psychological wellbeing of those affected by cancer may prevent a worsening of circumstances and may reduce the use of healthcare services<sup>18</sup>. Such support may also enable those affected by cancer to return to work more quickly<sup>19</sup>. Consequently, harnessing the support of community-based organisations will help to reduce the costs associated with worsening health and the increased, and in some cases inappropriate, use of healthcare services following a cancer diagnosis.

**WHY...** is one such organisation that supports psychological wellbeing, ability to return to work

and informs best practice on how to enable those affected to live well with and beyond cancer; all of which are key implementation recommendations of the NHS strategy.

At **WHY...**, we provide support for those affected by cancer at all stages of their cancer experience. Support is provided from diagnosis, during treatment, and for post-cancer circumstances. Importantly, **WHY** offers support for those affected by terminal illness and cancer-related bereavement. Psychosocial support such as that provided at **WHY** has been shown to be particularly important for those bereaved due to conditions such as cancer. An estimated 30% of caregivers exhibit symptoms of clinical depression following a bereavement. Also, 20% are estimated to experience persistent and complicated grief which is characterised by high levels of distress and an inability to fulfil the demands of daily life<sup>20</sup>.



We Hear You supports children, young people and adults offering up to 16 counselling sessions free of charge. Counselling takes place each week, at the same time and place with the same counsellor. This approach helps to ensure regular contact and consistent support is provided and ensures that the client sees the same counsellor throughout their counselling experience with **WHY....** All counsellors at **WHY...** are highly skilled and experienced in

**\* WHY... supports those affected by cancer at all stages of their experience**  
**\* Counselling takes place each week, at the same time and place with the same counsellor**

supporting people affected by life threatening conditions. Our counsellors use the psychodynamic and/or integrative or the person-centred approach. All counsellors are required to be registered with an

accreditation body such as the British Association for Counselling and Psychotherapy (BACP) and We Hear You as an organisation is an associated member of the BACP and adheres to its guidelines for best practice.

This evaluation was carried out by a researcher from the University of Bath as part of her *MSC* in Health Psychology with the full support from We Hear You. It received Bath University ethics approval in April 2016.

The aims and objectives of this project are outlined below: -

### Aims

To conduct an evaluation of the We Hear You counselling service to understand the impact on the lives of our clients. We also wanted to identify areas of best practice and opportunities where further development, research and improvement would be required. Specifically, we were interested in measuring the impact of **WHY...** on clients' psychological wellbeing and depression.

- To evaluate the impact of the We Hear You service on clients, and to assess the impact of the We Hear You service on psychological wellbeing and depression
- To understand the experience of patients and their supporters

### Objectives

- To conduct interviews to understand how the We Hear You service has an impact – asking about use of healthcare services, emotions, practical and work-related impacts
- To measure whether psychological wellbeing or experience of depression improves upon attending the We Hear You service

The We Hear You Adult Service Evaluation was designed in collaboration with an Advisory Board. The Advisory Board comprised of six members, each of whom had been clients of the **WHY** service, or had experience of cancer.

Bath University, department of psychology ethics approval was given in April 2016.

50 clients were identified as eligible for the research. Eligible participants were identified as those aged 18 years and over who had recently joined the **WHY...** service and had had at least two counselling sessions before contact was made. Of those identified 24 (48% of eligible clients) were successfully contacted by telephone (no messages were left on voicemails and our researcher was unable to speak to the remaining eligible

clients) and 14 (28% of eligible clients) were sent information documents after the researcher had explained the nature of the activity and ascertained if the individual would be interested in taking part.

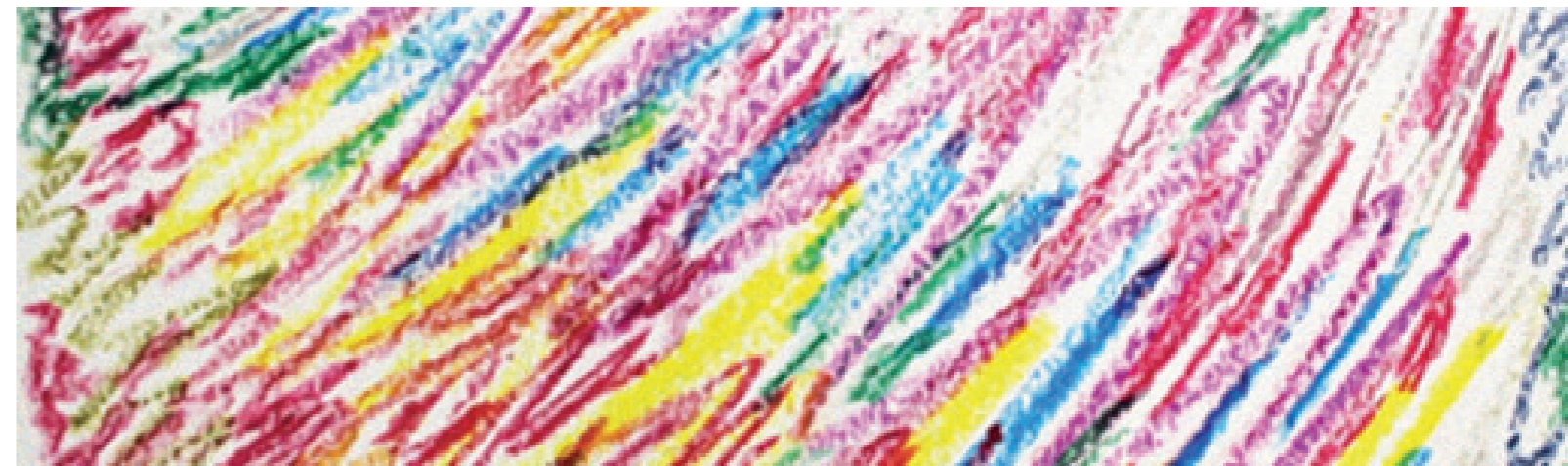
Overall, six participants, 42% of those who were sent information relating to the research, (three patients and three supporters) completed each stage of the evaluation. Seven participants completed all stages bar the last survey which had six participants.

It is acknowledged that the overall number of participants for this study is relatively small, this reflects the short time frame available for interviewing and survey completion, of just under three months. This limited our ability to engage with more clients than we did. This study is a pilot project and has provided a

valuable opportunity for us to test suitable methods for recruitment as well as measurement of impact. We have learned a great deal as a result and this will only improve our evaluation activities. For example, we now know that a mixed methods approach will work more effectively in the recruitment of participants, as we found that we could not contact as many people by telephone as we had hoped.

The average age of participants was 47 years, all participants were female with 85% identifying themselves as heterosexual, 85% were White British, 57% described their religion as Christian and 43% as no religion. Participants had been affected by a range of cancers, including breast, endometrial and brain cancer.

A full methods analysis can be found in Appendix 1.



# Stages of data collection

## First stage – pre-counselling measurement

Two validated tools were used at this stage, the Measure Yourself Concerns and Wellbeing tool<sup>21</sup> (MYCaW) and the Patient Health Questionnaire-9<sup>22</sup>. The MYCaW tool has been specifically designed to evaluate the impact of psychosocial cancer care services on the psychological wellbeing of clients. The tool was used for this evaluation as it addressed the objective of measuring the impact of the WHY service on psychological wellbeing and it has been validated for use with a range of cancer types<sup>23</sup>.

Also, it combines qualitative and quantitative methodology which allows a richer understanding of participant experiences<sup>24</sup>.

Participants also completed a PHQ-9 form, which is a brief and validated screening tool for depressive symptoms. The PHQ-9 requires participants to identify how frequently they have experienced each of the nine items (i.e. feeling down,

depressed and hopeless) in the previous two weeks.

The PHQ-9 was selected as it has been validated for use with cancer patients and for use with the general population<sup>25</sup> which is appropriate for the mixed sample of patients and caregivers. Secondly, the PHQ-9 takes minutes to administer compared to other tools which can take as long as 30 minutes. As such, participant burden was minimised<sup>26</sup>. However, one limitation of using this questionnaire is of how physical symptoms linked to cancer may be inaccurately attributed to symptoms of depression<sup>27</sup> and may lead to over-diagnosis of depression in cancer patients. Therefore, the PHQ-9 may not be the most appropriate tool to measure depression in those with chronic illness without separating the physical and psychological symptoms of depression<sup>28</sup>

## Second stage – Interview

For the second stage, participants were invited to an interview approximately two weeks after the first stage.

Interviews addressed the objectives of the evaluation in a broader context, with participants recounting the general impact of cancer and counselling on their lives. Interview questions asked participants about their experience of counselling (i.e. “Was the service what you expected it to be?”) and about the impact of cancer (i.e. “What do you feel are the main ways cancer has had an impact on you and your family?”). Interview questions were designed with guidance from the WHY Advisory Board.

## Third stage – post-counselling measurement

For the third and final stage, participants were asked to complete the MYCaW follow-up form, a second PHQ-9 depression screening form and a WHY evaluation form. The final stage was conducted once participants had completed their counselling sessions, which was at least two weeks after the interviews.

## Interview Questions

In the box below are the interview questions our researcher asked.

### Service evaluation of We Hear You adult counselling service 2016

#### Introduction to the research

(Researcher to introduce the work and explain why we are collecting this data and that all data is confidential and that the interview can stop at any time)

1. Have you had counselling before? (If yes, what type? And when?)
2. How did you hear about our service?
3. And why did you decide to refer yourself?
4. Is the service what you expected it to be?

#### Cancer

5. What do you feel are the main ways that cancer has impacted on you and your family?
6. Have you used/been directed to any other services to support your needs? (If so what?)
7. How often do you meet / speak to your CNS since diagnosis? (PATIENT ONLY)
8. How often do you meet / speak to your GP since you have been affected by cancer?
9. Since starting counselling with WHY...have you felt more able to
  - a. Manage your work responsibilities? [IF person is working – refer back to demographics]
  - b. Manage your home responsibilities? (Such as cooking, cleaning, finances)
10. Have you felt more able to manage your own feelings? (Such as coping with emotions, and follow up with: if so/not, how have you managed them?)
11. Have you felt more able to support your dependents and their wellbeing? (Such as practical support – taking children to school - or emotional support – talking about feelings – If so, how?)

#### Living with cancer

12. How has having cancer affected other aspects of your life? (Being active? How often do you see friends? Have you changed your diet at all? Side effects from treatment?)
13. Do you feel you are as physically and mentally active as you were before being affected by cancer?

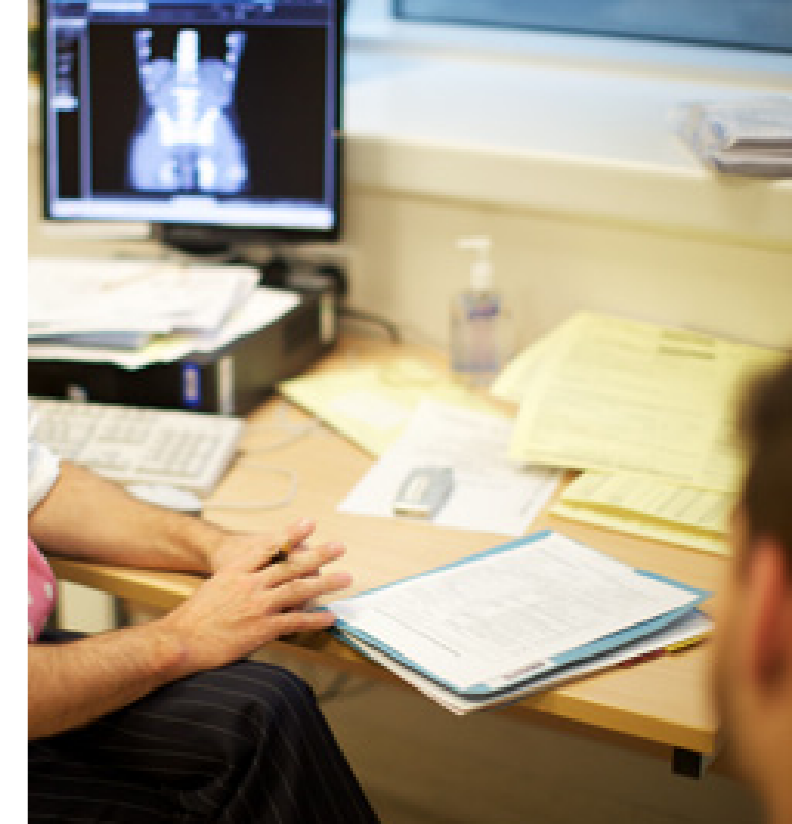


Figure 1

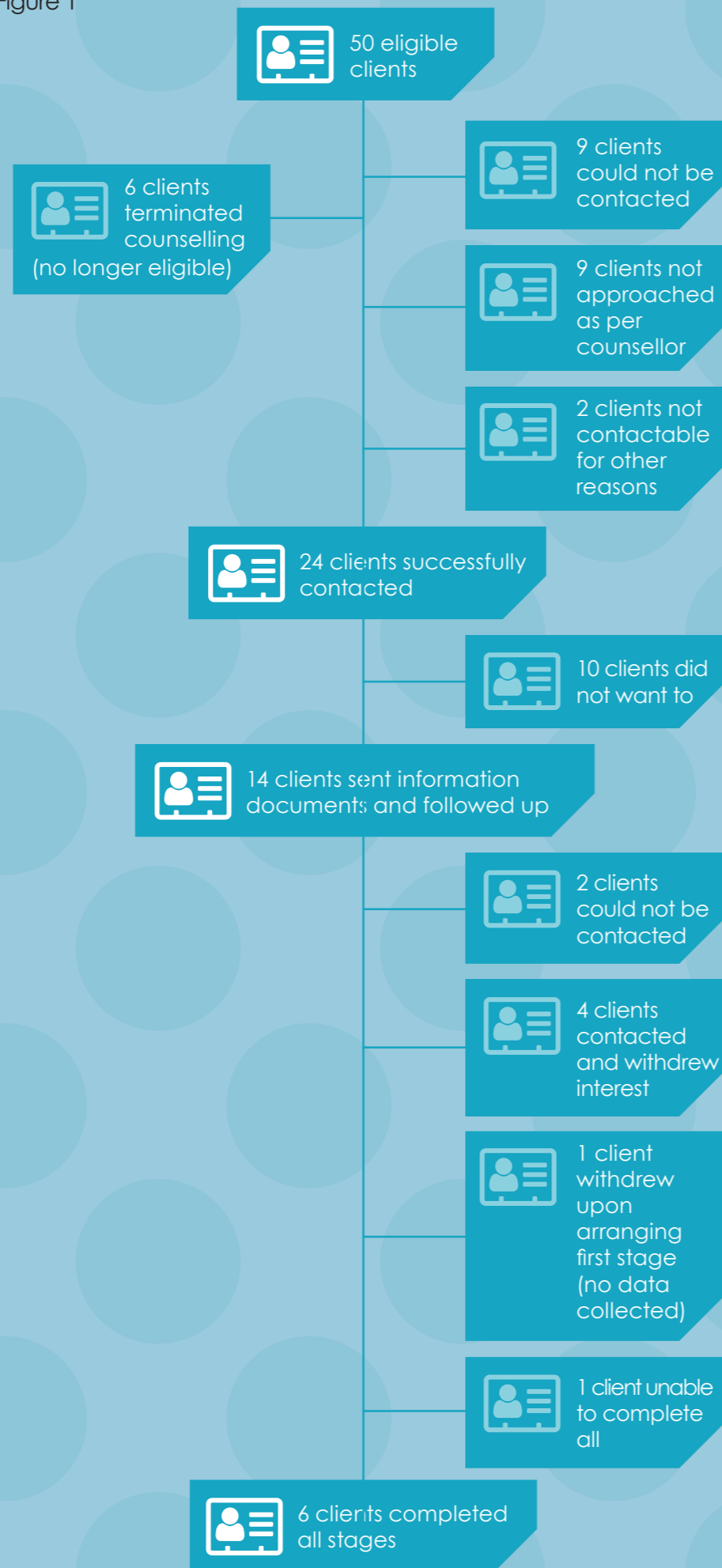


Figure 1. A consort flow diagram of the recruitment process. Analysis of differences between responders and non-responders was not possible as the relevant information had not been collected at the point of non-participation.

## Chapter 3 Results

### Interview analysis

Three main themes were identified in the interview analysis

- 1. Impact of cancer**
- 2. Impact of counselling**
- 3. Best practice and learning**

There were many areas that affected both patient and supporter with only marginal differences and as such data has been presented jointly unless specified.

Within each theme, subthemes were identified and are explored below in more detail.

#### 1. Impact of cancer

- a. Impact of treatment
- b. Caregiver burden
- c. Impact on family
- d. Use of healthcare services
- e. A life changing experience
- f. Benefit finding

#### 2. Impact of counselling

- a. Adjustment and coping
- b. Recognising and addressing needs of others
- c. Expressing emotions
- d. Restoration

#### 3. Best practice and learning

- a. Neutral support
- b. Regular support
- c. Relationship with counsellor
- d. Areas for development and learning



Theme 1:  
**Impact of cancer**

Clients reported a variety of ways in which cancer had had an impact on their lives. Patients discussed the impact of treatment and caregivers discussed the challenges of caregiving. However, the impact of cancer on family, use of healthcare services and of how cancer was a life changing experience were discussed by both patients and caregivers. Although cancer was largely (and understandably) a negative life experience, both patients and caregivers engaged with benefit-finding: improving their ability to cope with cancer by identifying positive outcomes of the experience.

The impact of treatment was a key issue for patients. The physical impacts of treatment such as skin conditions and cancer-related fatigue were discussed, as were the psychological impacts of social anxiety and vulnerability following treatment. Patients also commented on feeling abandoned upon completing their treatment regime.

*"when you're diagnosed and then you have all your radiotherapy and you're at hospital every week and everyone looks after you then as soon as you finish it's almost like you're just let go...you sort of feel a bit lost" (patient)*

*"I had skin problems from the radiotherapy...stressing me the most was dealing with...the fatigue which I didn't really expect" (patient)*

*"I didn't wanna go out and I was like that for quite a long time after [treatment]...I was...scared to go out...I didn't want anyone to...hit me cause obviously you're very tender after the radiotherapy" (patient)*

cancer... a life changing experience



*"not only did I lose my dad, I gained my mum in some respects because um I found I felt incredibly responsible for her...that was making me park my grief" (caregiver)*



Caregivers discussed a range of ways in which cancer had affected their lives. In particular, caregivers expressed how the impact of cancer was two-fold: they had additional responsibilities in caring for the patient, and as such, they felt unable to pursue a lifestyle of their choice.

*"the way it's impacted me most is probably time to do my own thing I think, and probably the same for my family" (caregiver)*



Cancer had a diverse impact on the family of patients. A diagnosis led to a change in familial roles, difficult communication and had an emotional impact on younger members of the family.

*"They [sons] had a great relationship [with their sister]... they were very close um so it was really a lot of struggle for them but the main way we saw them getting affected... my little one cries for everything now...he's like on the edge of being very emotional all the time...my other boy he's on the autistic spectrum so he got really affected by it...he developed OCD" (caregiver)*

*"It has changed the dynamics in my family because I'm the one being looked after rather than the one looking after everybody else" (patient)*

*"My kids sort of went a bit more reserved...they didn't know how to handle it... they didn't speak to me about it...it did feel like when I was diagnosed there was this massive gap between us" (patient)*

Both patients and caregivers reported using healthcare services for depression during their cancer experience and were given antidepressants. Fear of recurrence in patients also resulted in frequent visits to consultant post-treatment.

*"I was struggling a bit and of course emotionally I wasn't quite right so they [GP] gave me quite a lot of antidepressants" (caregiver)*

*"I went to see my consultant I think about four times after I'd found like, thought I'd found new lumps but they all came to be nothing and um each time I was just breaking down but nobody said anything" (patient)*

*"I just went to the doctors and just cried and cried and said exactly how I felt so then they did put me on Venlaxfaxine [antidepressant]" (patient)*

This finding needs further research, we do know that depression is prevalent in those affected by cancer from the literature, and psychosocial support is indicated as a relevant support method to use. However we can't comment further about why health professionals in this sample appeared to prescribe antidepressants and whether or not this was the only psychological support offered to participants as this data was not collected.



*"My lifestyle has completely changed and it's accepting that and accepting what I can do and what I can't do... everything has changed; my diet, my socialising, everything, yeah, my mobility, my working" (patient)*

**Cancer had had a life changing impact for all those affected. Clients described the shock of diagnosis, of the need to adapt to a new lifestyle and of how they will never resume their pre-diagnosis lifestyle. Loss of a loved one was also a significant, life changing impact.**

*"the recent impact is that you know, dad's gone" (caregiver)*



*"Cancer is just a real shock to the system in every which way" (patient)*

*"The main ways? I think it just changes your life completely...as soon as you hear cancer, your life changes completely. You are not the same person...I don't think there is any factor...that did not change in my life or my family life" (caregiver)*

The similarities between the impact of cancer on patients and caregivers was higher than we had anticipated, which is why we have not pulled out separate themes to more extent in this report. Although the negative impacts of cancer are well known and documented we were also encouraged by the level of positive benefits that people felt – the awareness of health in general.

The impact of cancer was both psychological as well as physical and both were intertwined. The psychological approach helped those we spoke to deal with not only their psychological wellbeing but also to manage the physical symptoms of cancer treatment e.g. fatigue and body image. This very much supports the models of integrated care across tertiary, secondary, primary and community care and self-management and long term wellbeing.

**Despite being a challenging experience, those affected by cancer engaged with benefit-finding, which is a positive coping strategy. A strengthening of familial relations, an increased appreciation for the value of life and greater engagement in health protective behaviours were important benefits cited by participants.**

*"I just think it's reinforced life's too short um and you know, I think for me, life is more about enjoying what we've got now than worrying about really what's around the corner as much perhaps I might have done in the past...it reminds you a bit that life is precious" (caregiver)*

*"I would say you know it [father's cancer] has also changed my relationship [with mother] for the better, we're very close" (caregiver)*

*"I don't really go to the doctor... but um I did go recently just because I had a lump in my breast which I knew was a cyst but I just thought you know it's good to get an ultrasound just so they can measure it and track for future so I suppose this thing with my mum kind of prompted me to go up and do that...you should look after yourself and get things checked when you can" (caregiver)*

## Theme 2: Impact of counselling

Clients felt that counselling had an important impact on their ability to adjust to their cancer experience. Following counselling participants felt more aware, and able to recognise and address the needs of those around them (including dependents), and that counselling supported them to express emotions. The counselling also helped by encouraging positive coping strategies. Importantly, counselling with WHY... also enabled clients to understand how, and feel more able to, move forward from and manage their cancer experience.

Five out of the six (83%) participants who completed the WHY...survey felt the counselling service was as they expected and upon completing counselling and completing the project five out of six (83%) participants said that they felt more able to manage the challenges of the future, whilst this can't be wholly attributed to counselling alone, as there were other external factors that weren't measured (eg cancer going into remission, being given the all clear or if someone was bereaved), it does give a clear indication of the

impact of the WHY... counselling service. It was encouraging to see that all participants with children felt more able to support them. The counselling helped participants to deal with their emotions and the emotions of those surrounding them. Counselling also helped those we interviewed to understand their situation, which in turn helped them to adjust more adaptively

to their cancer experience, eg communicating more openly and honestly with family members, learning to take time to deal with the psychological as well as the physical outcomes of cancer. Those we spoke to felt better equipped to manage fatigue, to return to work and support themselves and those around them.

**Counselling with WHY... helped those affected to adjust more adaptively to their cancer experience. WHY... counsellors encouraged positive coping strategies in the management of fatigue and regulation of emotions. Importantly, counsellors also enabled those affected to recognise and challenge maladaptive coping behaviours, such as excessive alcohol consumption.**

*"we talked about fatigue and how I'd have to pace myself...not to do so much in one day...me and the counsellor together coming up with those ideas so it helped... practically, things I never did before" (patient)*

*"you become quite emotional about normal things because when you're getting over cancer it's like normal things and normal stresses...become massive...I was more able to cope with, I was more able to work through those" (patient)*

*"I drank a lot when he died, when he was sick...I don't drink as much now...I did recognise it in the counselling sessions... drink was a nice way to not feel the overwhelming sadness that I felt when I didn't have a drink...I never felt...I was out of control...I don't need and I don't rely on it anymore" (caregiver)*



“counselling helped me understand that I’m not the only one finding it difficult”

Clients described how counselling enabled them to understand how their cancer experience affected others around them. Recognising the contribution of family members, understanding how each of those affected handle the situation differently, and feeling able to tend to the needs of dependents were all important outcomes of WHY... counselling sessions.

“it’s [counselling]... enabled me to... take on board how they [children] feel as well, cause you sort of shut yourself off and you think nobody actually cares how I feel... they were trying to cope in their own way” (patient)

“if you are doing better, you can be better for them...I was able to help them, that’s what counselling does to me, I feel better therefore I’m better with my family” (caregiver)

“It [counselling]...helped me understand that I’m not the only one finding it difficult...I would be really frustrated with my auntie...leaving a hurricane of mess...there’s more for me to do, not less...made me realise...psychological help... is more important than having someone...just cook for you... she finds it difficult too and she’s coping as best she can” (caregiver)



Counselling also helped clients feel more able to move forward from their cancer experience and construct a post-experience routine and lifestyle. This included enabling those affected to return to work.

WHY... counselling helped clients to communicate their emotions more openly and honestly with those around them, particularly with their children

“I’m...much more able to be vulnerable with the children... there has been a softening between us...more open and more able to communicate” (caregiver)

“I’ve become a lot more honest about how I feel...rather than putting up this happy front where nobody actually knew how I felt” (patient)

“it’s...enabled me to speak to them [adult children]...openly and honestly, tell them exactly how I did and do feel...we sort of just talk about anything and everything...it’s much better” (patient)



“the counselling came in because it’s harder to just move on yourself when you’ve spent a year having treatments...it’s harder to work out what you’re actually moving on to cause your life is turned upside down and...has changed so much” (patient)

“I remember saying to the counsellor, the first session I felt like I was waiting for something to hit me...I knew what had happened and then it still felt like I was waiting...it was time that I was waiting for... functioning without just being overwhelmingly sad all the time...I needed to cut myself the slack to grieve properly” (caregiver)

“talk through going back to work and then now, yes it’s easier, it’s still difficult to cope... but it did help me sort of pace every week to talk about how far I’d got and when I’d be able to do it you know so it did help me to get back to work” (patient)

“I’m starting to concentrate more so that’s quite a good feeling actually sort of felt less fogged in the head” (patient)

### Theme 3: Best Practice and Learning

There were many ways in which clients discussed how WHY... counselling helped them. Simply being a form of neutral, anonymous support was helpful, as well as the security of having a regular slot for the counselling session. Clients discussed the importance of the relationship they had with their WHY... counsellors and also emphasised how the charity offered continuity of care with the same counsellor being reassigned to clients who were attending the service on future occasions.

In some cases services weren't always reachable, due to the wide geography that WHY... covers and some participants had had difficulty in travelling to venues.

Waiting times for appointments was mentioned, but also acknowledged that the wait was far shorter than for other avenues of support participants had been offered. It is important for WHY... to be clear on the waiting times to ensure expectations are managed and met.

The service that WHY... provided was seen as unique, providing emotional support to those affected by cancer. An area for development and improvement for WHY... is that often participants didn't know what support they needed until it was offered to them. However, once they received counselling they found it very beneficial. A way to

address this could be to look at other ways of reaching out to those that could benefit from the support of the charity, offering different types of emotional support eg group counselling, art therapy or couples counselling could provide other ways and means for individuals to benefit from the support that WHY... has to offer.

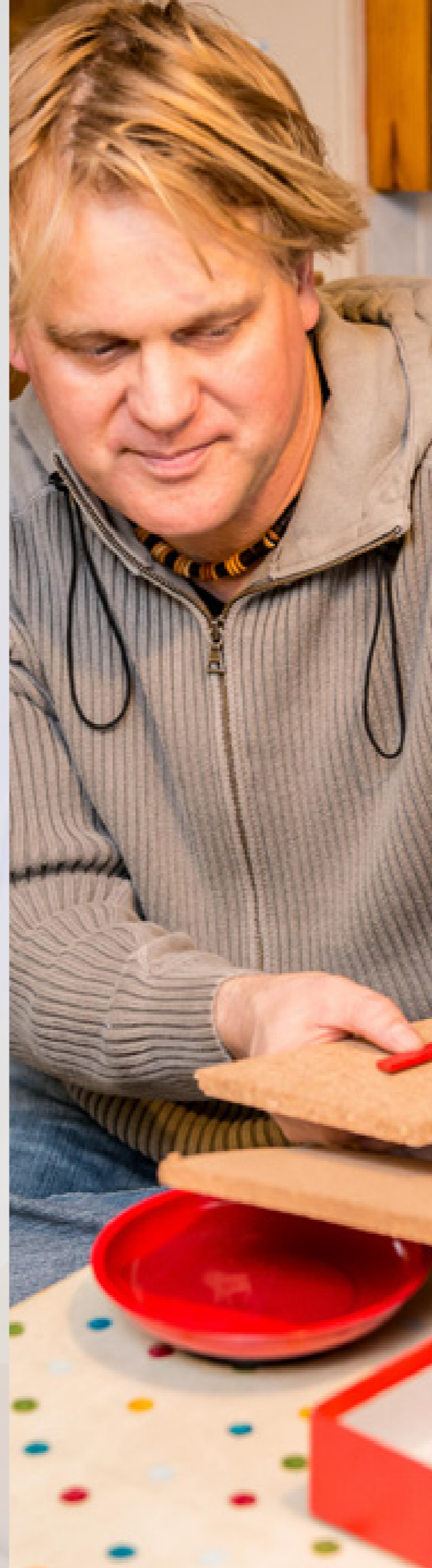
*"talk through going back to work and then now, yes it's easier, it's still difficult to cope...but it did help me sort of pace every week to talk about how far I'd got and when I'd be able to do it you know so it did help me to get back to work" (patient)*

**Counselling also helped clients feel more able to move forward from their cancer experience and construct a post-experience routine and lifestyle. This included enabling those affected to return to work.**

*"the counselling came in because it's harder to just move on yourself when you've spent a year having treatments...it's harder to work out what you're actually moving on to cause your life is turned upside down and... has changed so much" (patient)*

*"I remember saying to the counsellor, the first session I felt like I was waiting for something to hit me...I knew what had happened and then it still felt like I was waiting...it was time that I was waiting for... functioning without just being overwhelmingly sad all the time...I needed to cut myself the slack to grieve properly" (caregiver)*

*"I'm starting to concentrate more so that's quite a good feeling actually sort of felt less fogged in the head" (patient)*



**Having a neutral form of support was a benefit of the WHY service as clients felt able to discuss any concerns they had and to appreciate an alternative perspective. Also, clients felt that through discussing their problems with their WHY... counsellor, they didn't feel they were burdening their loved ones.**

*"good having someone... anonymous...to help you make sense of it all" (caregiver)*

*"it's [counselling] enabled me not to be having to dump my emotions or in some possible non-verbal way on the children...not having had to bring it all back home" (caregiver)*

*"I really needed to talk about things...it was nice to be able to speak to somebody outside the family...rather than burdening my children with how I felt" (patient)*

**Having a regular, weekly slot was also identified as an important benefit of the WHY... service. Clients also discussed how having the flexibility to have as many as 16 sessions allowed them to recognise the impact of counselling.**

*"I know every week, I have my Tuesday morning and I'm coming to see someone and that makes all the difference" (caregiver)*

*"I didn't really know if I had any if there was any benefit...after 5 sessions...it is good having the option of having the extra 10... it is helping...I do like the regular slot every week" (caregiver)*

Clients reported having positive experiences with their WHY counsellors. Clients felt able to discuss anything with their WHY... counsellor, and felt able to openly express their emotions.



*"I felt really relaxed with my WHY counsellor and it was quite nice and I did cry but she was a really nice lady" (patient)*

*"It was time to be able to talk just about me and what I was going through...have that space in the counselling room to talk about me and not be talking to anyone else that doesn't want to hear it" (patient)*

Continuity of care was also discussed. WHY... offered one caregiver the same counsellor they had had previously when circumstances changed, much to the relief of the client.

## What is the impact of the WHY... service on those that use our support?

WHY... offers support to children, young people and adults affected by cancer or life threatening conditions whether they are patients, caregivers, family members or friends. WHY... is the only organisation in the locality providing this level of support and is an accessible service with counselling provided in a variety of locations as well as online. Importantly, WHY... counsellors possess specific knowledge about cancer, which is highly valued by clients.

*"you have to have some kind of connection...you have to feel like they're going to help you...when my daughter passed away...I couldn't imagine starting from zero... came here and saw my therapist...I thought yay, I do not have to start from the beginning" (caregiver)*

## Interview analysis

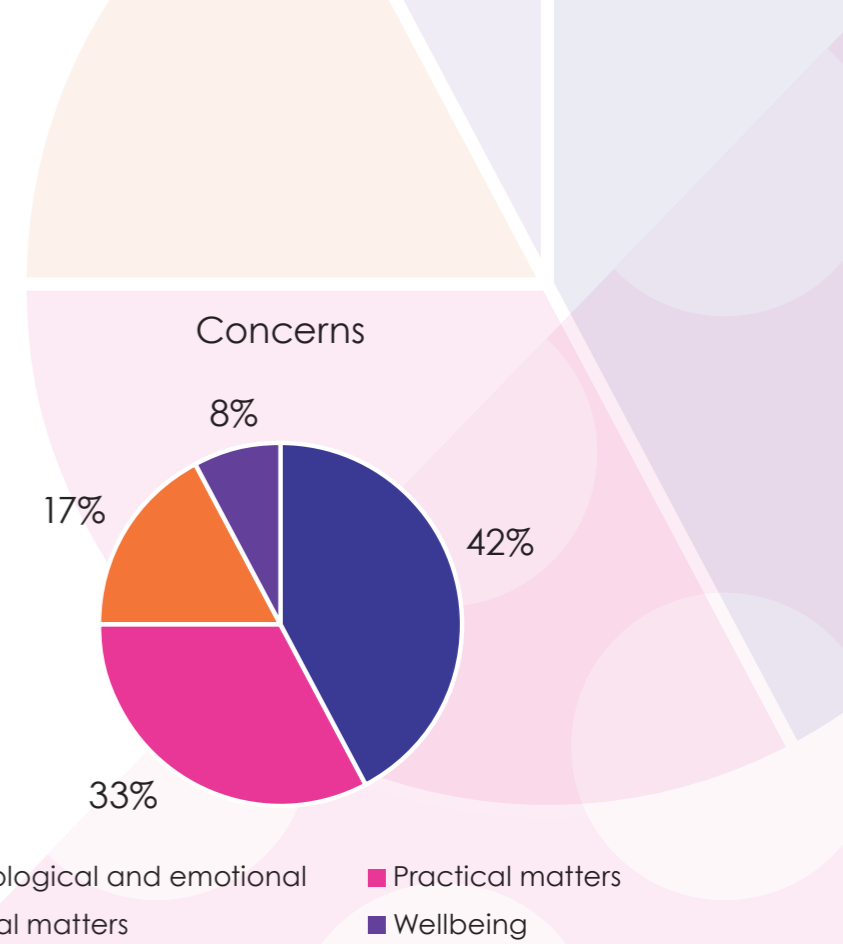
### MyCAW and PHQ- 9

All seven participants completed both the MyCAW and PHQ-9 surveys at the beginning and end of our research. This enabled us to analyse any changes in responses. A final survey which had been developed by WHY... was also completed at the end of our research by six of the participants.

### Measure yourself concerns and wellbeing

Each participant listed two concerns on the MyCAW form along with one question asking them to rate their wellbeing at that point in time, on a scale of 0 (as good as could be) to 6 (as bad as could be). Both concerns were then rated on a scale of 0 (not bothering me at all) to 6 (it bothers me greatly).

Forty-two percent of all concerns reported by participants comprised of problems relating to psychological and emotional concerns, such as managing bereavement, changes and adjustment to "new" life for example reducing work hours, impact on relationships and treatment effects. Of these, 40% related to adapting and coping, 20% were emotional problems, 20% concerned family and relationships and 20% related to regaining balance and normality.



Thirty-three percent of all concerns related to practical matters. Within this category, 75% of practical concerns related to work and 25% related to finance.

Seventeen percent of all concerns reported were physical. Fifty percent reported physical concerns not related to cancer and 50% reported concern about cancer recurrence.

The final 8% of all concerns were concerns about wellbeing. The one concern reported related to nutrition.

For concern one, there was a significant improvement in the psychological and emotional concerns expressed (ie a reduction in concern) when comparing pre-counselling to post-counselling scores<sup>29</sup>. For the second problem participants listed and for the wellbeing

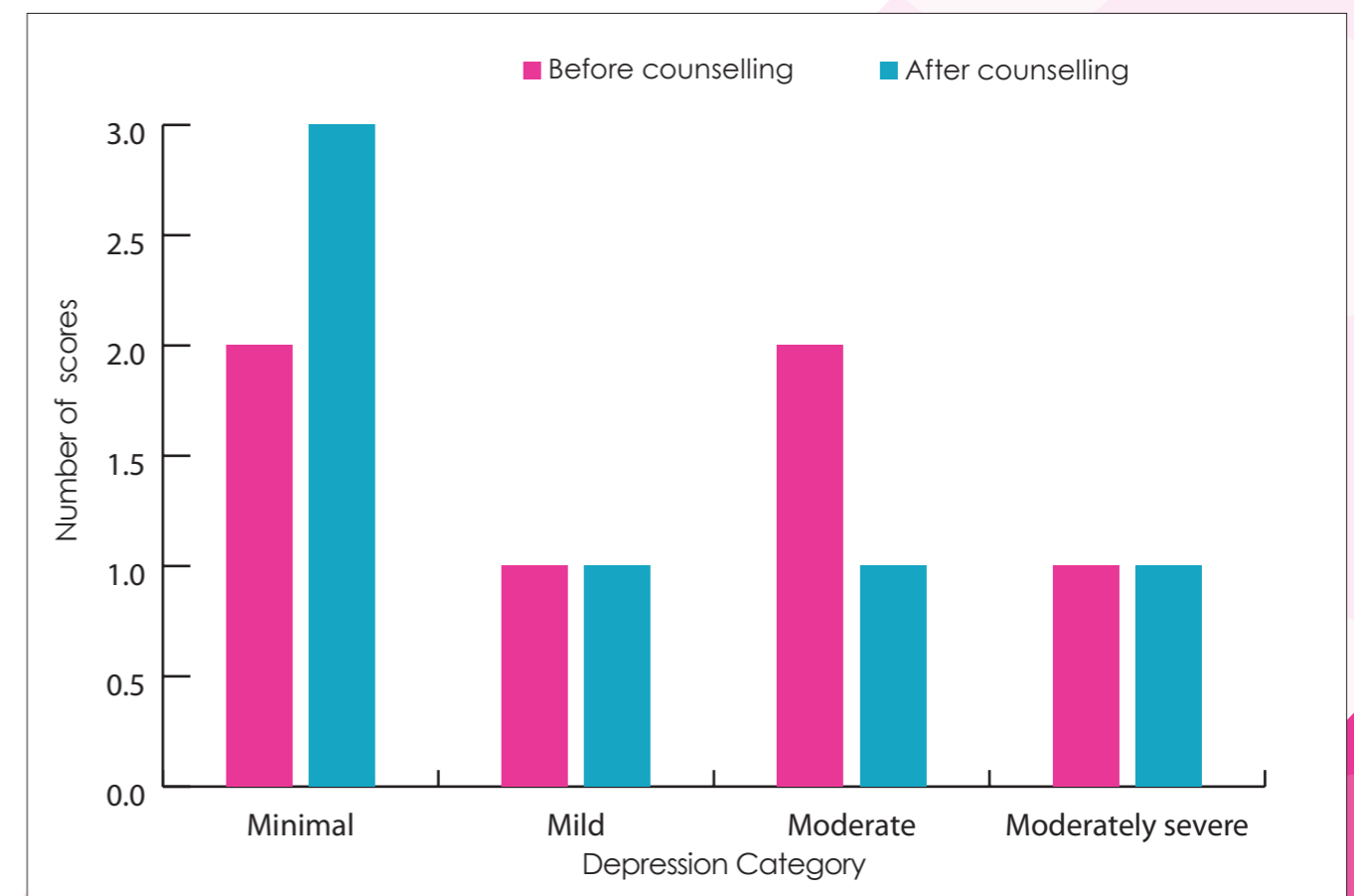
question, the pre-and-post counselling scores were also reduced but to a lesser effect. However, they still demonstrated a positive trend towards improvement as scores indicated participants were feeling less concerned about problem two and also indicated how participants felt they had better wellbeing.

The pie chart represents the main concerns that participants had with the most frequent concern (42%) being psychological and emotional, such as exhaustion or managing a bereavement. The second most frequent concern (33%) related to practical matters (returning to work, managing a home), the third (17%) to physical matters around health and the fourth (8%) to wellbeing eg partners, children or individuals wellbeing.

Table 2  
Distribution of depression severity

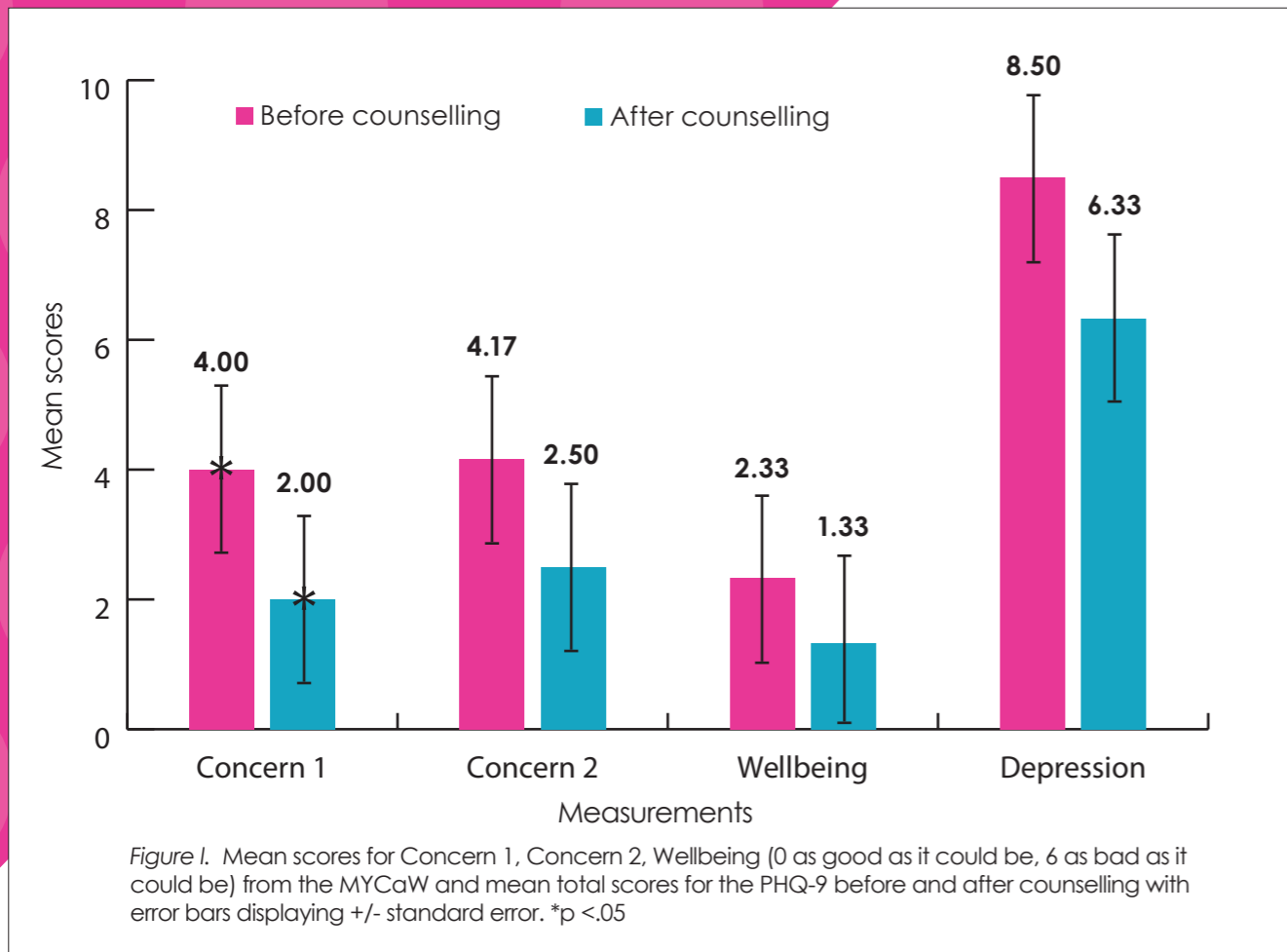
Categories of depression severity (score range)	Before counselling n (%)	After counselling n (%)
1 Minimal (0 – 4)	2 (33)	3 (50)
2 Mild (5 – 9)	1 (17)	1 (17)
3 Moderate (10 - 14)	2 (33)	1 (17)
4 Moderately severe (15 – 19)	1 (17)	1 (17)
5 Severe (20 – 27)	-	-

Table 2a



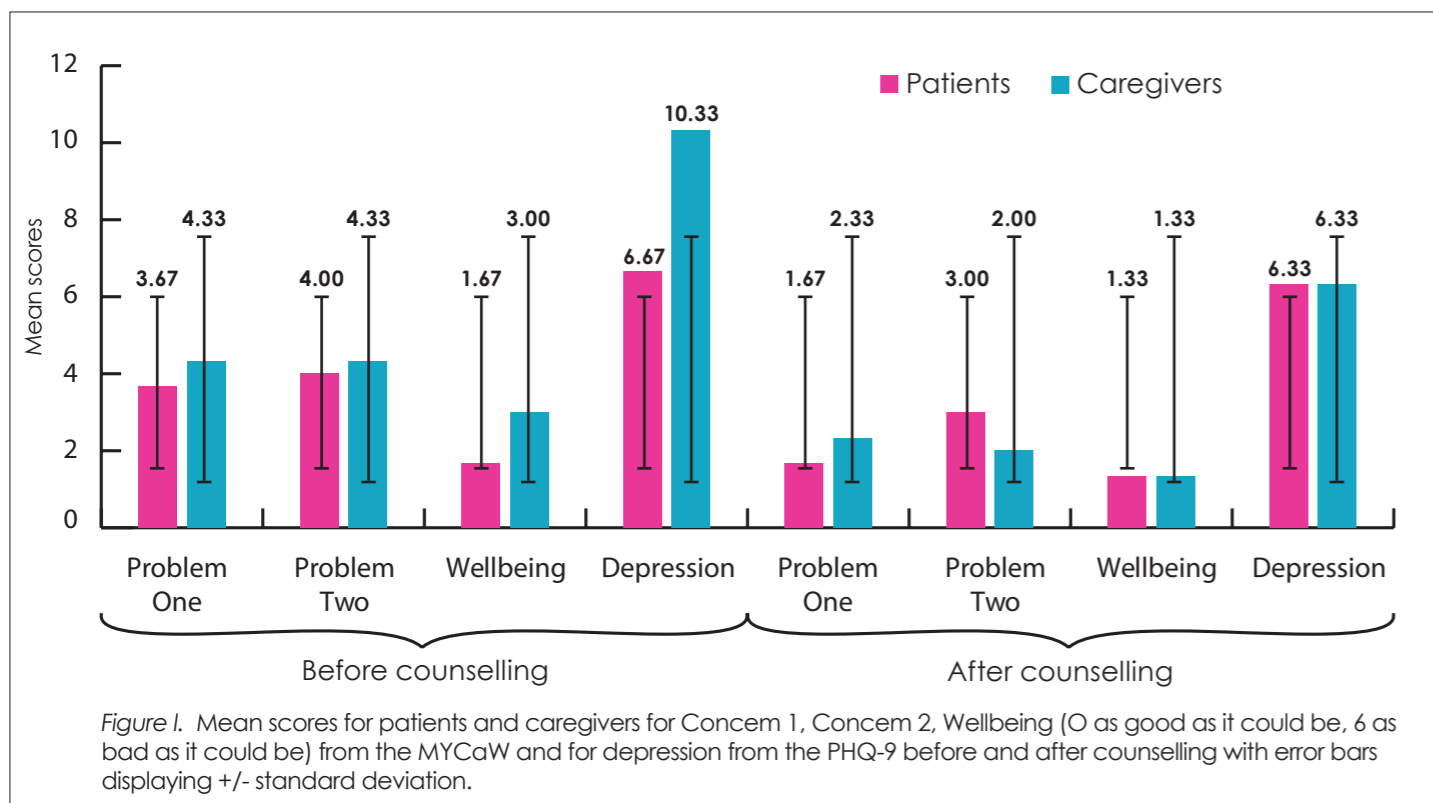
Due to the limited sample size, it was not possible to analyse the differences between patients and caregivers. Table 2 and 2a show where participants fell on the depression scales before and after counselling, showing a trend after counselling to more individuals within the minimal category.

Table 3 presents a breakdown of descriptive statistics for each group for MYCaW and PHQ-9 scores before and after counselling. It is interesting to note that after counselling more participants had moved towards minimal depression levels.



### Patient Health Questionnaire-9 (PHQ-9)

Seven participants completed the pre-and-post counselling depression scores which also showed an improvement (ie a reduction in depression levels). Although this improvement was not significant, it was certainly trending in the desired direction. The average score before counselling (Average score = 8.5) represented a severity category of mild depression (please see the table below), which remain unchanged for the post-counselling mean (Average score = 6.3) which also fell into the mild depression category, but was however reduced.



## WHY... survey findings

The WHY... survey was carried out at the end of the research and six participants completed it. The survey was developed to elicit more detailed quantitative information in relation to participants' wellbeing and overall views on various aspects of their cancer experience. Two surveys were designed, one for carers and one for patients and the questions asked were divided into two sections, questions associated with peoples' experience of counselling and the impact of cancer on patients and families.

A key finding in this survey was that 83% of participants felt the WHY counselling service was as they expected.

### Employment and healthcare contact

A high proportion of participants were employed (83%) and the majority (80%) part time. It must be acknowledged that this may relate to the sampling methods employed for this project – those who work part-time were

more able to be available to participate during working hours compared to those who work full-time.

Contrary to research<sup>30</sup>, of those who are employed, 80% of participants did not need to reduce working hours due to their cancer experience and only 17% reported that their partners had to stop working due to cancer. However, this may be attributed to how most participants already worked part-time and therefore, were more able to be flexible with treatment and appointment schedules.

83% of participants described their frequency of contact with their GP as 'not very often'. However, it is not possible to attribute this infrequent attendance to the support of WHY... alone. Also, it was evident during the interviews that participants had been in touch with healthcare professionals for psychological and physical health problems during their cancer experience, but at time points that were not captured by the survey. This

may have had an impact on the data we collected in our limited time frame.

100% of patients in sample reported contacting their Cancer Nurse Specialist 'not very often' which is contrary to our anecdotal findings that those with raised anxieties contact their specialist nurse or doctors more frequently.

More research is needed to explore the issues relating to employment, and healthcare contact for those experiencing cancer. Anecdotal evidence from clients using the WHY... service is that the support the charity provides them with helps to build their ability and in some cases confidence to manage their condition, be this through returning to work, less reliance on healthcare professions and medication and through managing relationships. The data in this project did not explicitly concur with this, however this could be for a number of reasons, which were not explored in this research.

Table 3

MYCaW scores (0 'as good as it can be' to 6 as 'bad as it can be') and PHQ9 scores (0 – 4 'Minimal', 5 – 9 'Mild', 10 – 14 'Moderate', 15 – 19 'Moderately severe' and 20 – 27 'Severe') total (n=6) and by patient (n=3) or caregiver (n=3) status

Measure (score range)		Before counselling Mean (SD)	After counselling Mean (SD)	Mean change Mean (95% CI)
MYCaW concern and wellbeing scores (0 - 6)	Problem one			
	Total	4.00 (1.67)	2.00 (1.41)	2.00* (1.06 – 2.94)
	Patient	3.67 (1.53)	1.67 (1.53)	
	Carer	4.33 (2.08)	2.33 (1.53)	
Problem two	Total	4.17 (1.17)	2.50 (2.07)	1.67 (.09 – 3.25)
	Patient	4.00 (1.73)	3.00 (3.00)	
	Carer	4.33 (.58)	2.00 (1.00)	
Wellbeing	Total	2.33 (1.97)	1.33 (1.37)	1.00 (-.33 – 2.33)
	Patient	1.67 (2.08)	1.33 (1.53)	
	Carer	3.00 (2.00)	1.33 (1.53)	
PHQ-9 depression scores (0 – 27)	Total	8.50 (6.44)	6.33 (6.71)	1.00 (-.33 – 2.33)
	Patient	6.67 (6.11)	6.33 (6.51)	
	Carer	10.33 (7.51)	6.33 (8.39)	

Note. \* p < .05



## The impact of cancer

Importantly, participants reported positive as well as negative impacts of their cancer experience. These findings reflect the theme highlighted during the interviews – benefit-finding. This is a positive coping mechanism whereby people identify the ‘silver lining’ during difficult and challenging times.

- 83% of participants reported how their cancer experience had had a positive impact on their sense of value to others
- 50% of participants reported a positive impact on their relationships with family, whilst the other 50% reported both a positive and negative impact

A varied experience of the impact of cancer on friendships was reported: 33% of participants reported a positive impact, 33% reported a negative impact and 33% reported both a negative and positive impact. This is consistent with existing research and would be an interesting area for future study.

- 50% of participants reported a negative impact of cancer on their own mental wellbeing, with 50% reporting both a negative and a positive impact

### Beyond cancer

Upon completion of the project, we asked participants to indicate how they felt about managing work, relationships and home responsibilities following their cancer experience. We cannot infer that the results listed below are wholly as a result of WHY... counselling, we do know however that each participant expressed how WHY... had helped them during the interviews, and this helps us to build a wider picture around the results of the survey results below.

- 83% of participants reported agreed or strongly agreed with how they feel able to cope with the challenges in front of them
- 33% of participants reported feeling concerned about the future

- 83% of participants agreed or strongly agreed with how they have strong relationships with those closest to them
- 66% of participants agreed or strongly agreed that they feel they have good mental wellbeing
- 66% of participants agreed or strongly agreed that they feel able to manage their work responsibilities; equates to 80% when scaled up to those that are employed
- 50% of participants agreed or strongly agreed that they feel able to manage their home responsibilities
- 66% of participants agreed or strongly agreed that they feel able to participate in the physical activities that they want to
- 83% agreed or strongly agreed that they felt able to make healthy lifestyle choices
- Of those with dependents, 100% agreed or strongly agreed that they feel able to support them

# Chapter 4

## Findings and Recommendations

### Key findings

Impact of cancer  
Our study highlighted that:-

- Cancer treatment has a physical and psychological impact on patients
- Caregivers not only experience the additional responsibility of providing care, but also have less freedom to pursue the lifestyle of their choice
- A cancer diagnosis affects all supporters of the patient – especially vulnerable family members such as children
- The psychological impact of cancer on both patients and supporters can lead to increased use of healthcare services, particularly for conditions such as depression
- Cancer is undoubtedly a life changing experience
- However, patients and caregivers identify benefits of their experience such as an increased appreciation for life and an improvement in health protective behaviours

#### Key Recommendations

1. WHY... to carry out further more in-depth work to understand the psychological impact of cancer on the patients and carers the charity supports,

to help the charity meet the needs of those accessing our support.

2. WHY... to review the Impact of different types of cancer on individuals accessing our service to understand the similarities and differences of emotional need
3. This work has shown how cancer impacts those surrounding the patient particularly vulnerable family members such as children and young people. The charity will review the impact of its children and young people's counselling service on those that use it and those that support and fund it.

#### Impact of cancer

Our study highlighted that:-

- Counselling with WHY... has helped clients to adjust more adaptively following their cancer experience such as through encouraging positive coping strategies
- Clients felt more aware of the impact of cancer on those around them, and were more able to meet the needs of dependents following WHY... counselling
- WHY... counselling enabled clients to communicate more openly with those

around them and more able to express their emotions, particularly with their children

- With the support from WHY..., clients indicated how they felt more able to move on from their cancer experience

#### Key Recommendations

1. WHY... to carry out a study to capture and evaluate the longer-term impact of the WHY... counselling service. This report offers a "snapshot" of clients experience over the course of their counselling with the charity. It would be valuable to measure the longer-term impact of the support provided, which would help the charity measure its longer-term outcomes.
2. WHY... to review the impact that the provision of its counselling support can have on individuals ability to self-manage their condition, For example, return to work, as well as their other key interactions such as with healthcare professionals, social services, financial support.

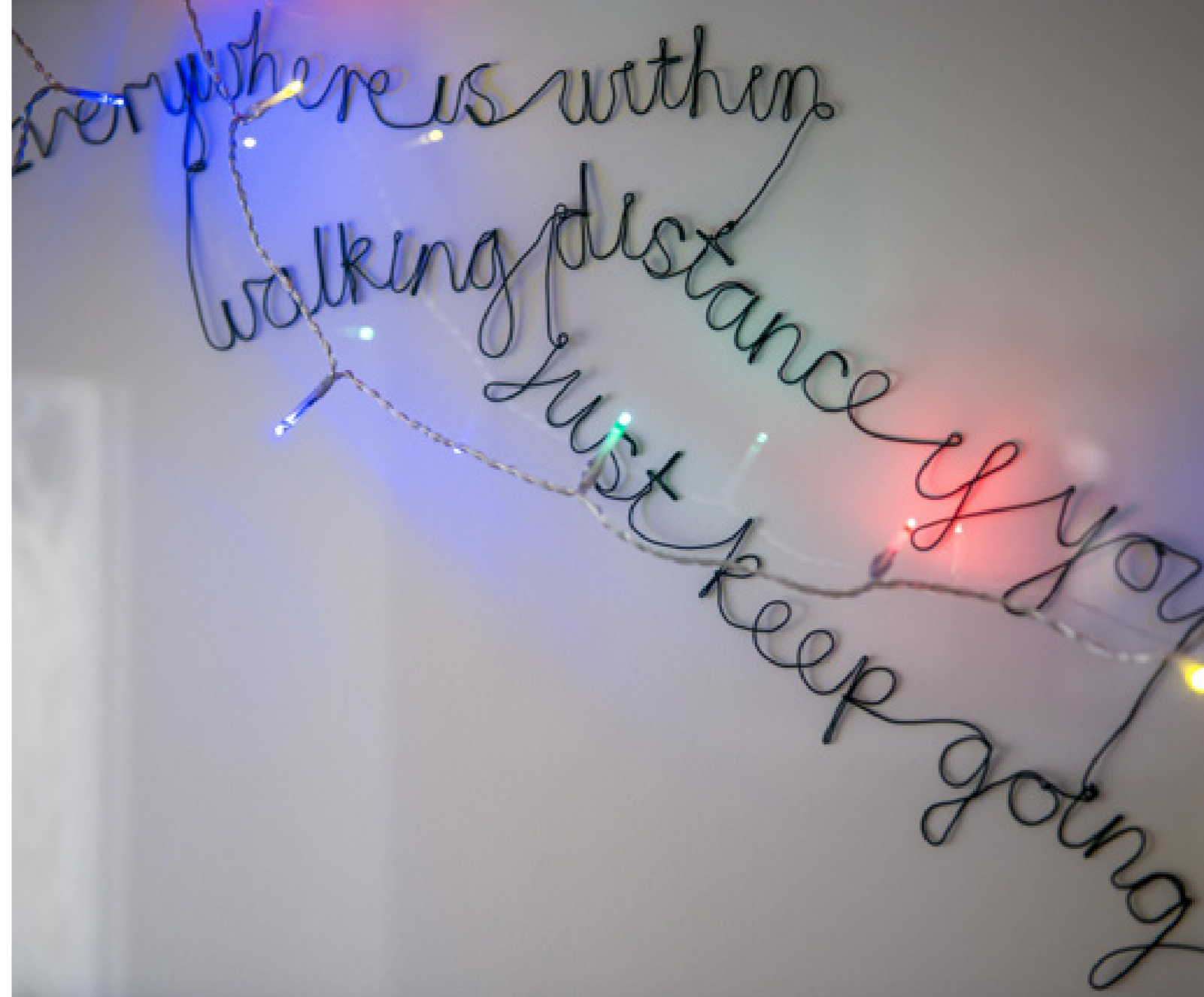




## Best practice and learning

Whilst learning more about the impact of the service on those who access our support we also learnt considerable amounts about how to collect data, and what tools to use to help measure the impact of our counselling. This section covers both these two areas.

- Clients valued having a neutral, anonymous individual as a source of support
- Having the option to attend as many as 16 sessions of WHY... counselling, as well as having regular, weekly slots were important benefits of the service
- Clients indicated how they had had positive relationships with their WHY... counsellors – a key feature in providing successful support
- Clients experienced continuity of care with WHY: being able to re-attend and have the same counsellor was an important benefit when circumstances changed
- Some participants indicated that the distance to venues could be a barrier to attendance.
- Some participants noted that they had had to wait for their counselling sessions, however they did acknowledge that the wait was much less than for other services they had been sign posted to. Clear communication to manage expectations will be key in development of the WHY... service.
- Participants indicated that they often hadn't known what support would be beneficial or what was available to them. However, on accessing counselling all participants said it had helped them in managing their cancer experience and had enabled them to adopt positive coping strategies. Further publicity and options of emotional support could be advantageous to WHY... in reaching a wider and more diverse group of people who may be struggling with understanding and know what support could be beneficial.
- Consideration on the evaluation and measurement tools currently used within the service and for future studies. The PHQ-9 and MYCAW tools used in this project worked well but it is important to consider their limitations and to also consider how other psychological support services are evaluated and measured to ensure the charities work can sit alongside other support interventions.
- WHY to consider the impact the counselling provided has within society in a more general context. This could be through the commissioning and/or undertaking of a social return on investment study or cost benefit analysis of the service that it provides. Anecdotal evidence emerged whilst carrying out this study that the support provided was impacting on families and beyond and it would be helpful to be able to quantify this in more detail for the development and improvement of the WHY... service.



## Summary

This report summarises a pilot project investigating the impact of the WHY... adult counselling service.

Importantly, we have been able to reveal some evidence which suggests that the unique WHY... service has a vital role in helping those affected by cancer in Bath and North East Somerset, Somerset and Wiltshire.

The WHY... service plays a key role within the community providing a quality, well respected and regarded

psychosocial support service. It helps patients and carers to self-manage their (or their partners) condition more effectively. This is a service which is helping to meet the objectives of NHS England policy (Five Year Forward View Cancer Strategy<sup>34</sup>) by providing psychosocial support in the community.

Having recorded a brief 'snapshot' of the client experience, we recognise the importance of conducting future studies with more rigorous

tools and larger samples. Funding for such work would need to be sort and secured in order for this work to be carried out.

Through securing future funding, WHY... can consolidate the findings in this report and gain an even deeper understanding of how community-based support is an essential component of whole-person cancer care. In doing this, we can reach all those who need the support and reduce service waiting times.



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- <sup>29</sup> See Appendix Two for full MyCAW survey questions and scoring methods.
- <sup>30</sup> Steiner, J. F., Cavender, T. A., Main, D. S., & Bradley, C. J. (2004). Assessing the impact of cancer on work outcomes. *Cancer*, 101(8), 1703 - 1711.
- <sup>31</sup> Simon, G. E., & Von Korff, M. (2006). Medical co-morbidity and validity of DSM-IV depression criteria. *Psychological Medicine*, 36(1), 27 - 36.
- <sup>32</sup> <https://www.england.nhs.uk/wp-content/uploads/2016/05/cancer-strategy.pdf>
- <sup>33</sup> <http://www.coreims.co.uk/>
- <sup>34</sup> <https://www.england.nhs.uk/wp-content/uploads/2016/05/cancer-strategy.pdf>



### Who we support

- Carers
- Children
- Friends and loved ones
- Patients
- Relatives
- Young people
- Anyone bereaved by cancer or other life-threatening conditions

### Where we offer counselling

- Bath (RUH and Twerton)
- Bradford on Avon
- Frome
- In various schools
- Midsomer Norton
- Online
- Group therapy
- Street
- Trowbridge
- Warminster
- Yeovil

We rely entirely on voluntary donations from our clients, local businesses, individuals, community groups and grant making trusts.

If you would like to support our work or find out more about the emotional support we provide please do get in touch.



we hear you

Cancer  
Counselling

### We Hear You,

Frome Town Hall,  
Christchurch Street West,  
Frome, Somerset, BA11 1EB



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