

Evaluation of the Blue Mountains Cancer Help Model

from the Perspective of
Clients, Carers and Healthcare Providers



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Acknowledgements and Contributions

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We acknowledge the contributions made by the Steering Committee: Ms Diana Aspinall, NBMML Director and long-standing health consumer activist; Ms Robyn Yates, BMCH Chief Executive Officer and founder; Dr Ilse Blignault, University of New South Wales School of Public Health and Community Medicine; Dr Louise McDonnell, University of Western Sydney General Practice Department; Professor Jenny Reath, Peter Brennan Chair of General Practice, School of Medicine, University of Western Sydney; Ms Annette Wickens and Ms Elaine Holman, BMCH consumer representatives; Mr John Stubbs, Chief Executive Officer of CanSpeak; and Ms Carolyn Hodge from NBMML.

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Last but not least, we acknowledge the BMCH members and others who took part in the surveys, interviews and focus groups, and all the stakeholders who attended the research workshop.

Preface – A consumer’s story by Annette Wickens

I was diagnosed with cancer in late 2007. I was a self-proclaimed "super woman", a wife and mother of four children running my own business. I led an extremely busy life. Most of 2008 was a blur of surgeries and treatments. I am an accountant, "a numbers person" as my oncologists noted, and this helped them tailor their discussions of what became my treatment plan. I always remember how fortunate I was to have such a great team of clinicians. Each treatment was crossed off my list with great anticipation. I was one step closer to putting this nightmare behind me.

In 2008 I also became a member of Blue Mountains Cancer Help (BMCH) and was able to link into the wholistic, ongoing model of care and support that is the focus of this project. The cancer diagnosis had a life-changing impact for both me and my family. I've realised the experience was not only my own cancer journey, but my family's journey. The effect of my cancer diagnosis in those early years on family dynamics was very distressing. "Awareness" and "acceptance" are the words we use now, but for a long while we were living a nightmare. The whole experience has given us confidence and I feel some relief that my children, who now live in different parts of the world, learnt such valuable lessons at such a young age. We know they have qualities such as strength, resilience, compassion and wisdom to draw on to help them get through their own life challenges. Most importantly, we know as a family that we are still connected and there for each other no matter what. We are ever so grateful for this and celebrate whenever we are together.

I am fortunate to have such a sensitive and caring family around me, for others it's a different story. As a community, I believe we should be looking at supporting our neighbours and friends who aren't so lucky. Blue Mountains Cancer Help is one such community organisation that is doing this.

Being a survivor of cancer is part of the journey. Finding a "cure" for cancer will not take away the issues surrounding "diagnosis" and "survivorship". We need to look beyond the medical model and find out what we can do to help ourselves. I personally think an integrative and wholistic approach is great as it allows for taking some active control over that "curve ball" you have been thrown. It felt good to have some assistance in helping with the side effects of chemotherapy, radiotherapy and surgeries. The nurturing hands of the therapist in reflexology sessions were so comforting. I also was able to relax my "overly-anxious" mind from the fear and distress of what was happening and to get some gentle stimulation of my lymphatics which had to be valuable.

Nearly seven years later, I am still able to avail myself of the subsidised therapies offered by BMCH. Every day I see the physical effects of my cancer and treatment—scar tissue damage, low energy levels and cognitive impairment. Stress and fear are things I manage. The opportunity to call a therapist and have acupuncture or lymphatic drainage is wonderful, along with having a chat with someone who understands. I still live a busy life. I've had to adjust and recognise that. At times I am fragile, especially when I am due for my check-ups (the "monkey on my back" as we call it). My plans for the future have changed, and I have learnt to accept the many effects cancer will have on our retirement, but the lessons learned far outweigh this and assist me in maintaining my quality of life. I look different and I see life differently now. I appreciate each day for the simple things such as the beauty of nature. Life is good.

Executive Summary

Cancer is a leading cause of the disease burden in Australia and has a major impact on individuals, families and the healthcare system. Cancer control is a national health priority area. With an ageing population and increasing rates of cancer diagnosis and survival, it is important that affordable, effective and safe cancer care and ongoing support is accessible to all Australians who need it.

Blue Mountains Cancer Help is a not-for-profit, community-based cancer support service based in Katoomba, New South Wales. There has been little research and there are few published papers on community-based cancer support services. This consumer-led project provided an opportunity to investigate the contribution of such a service to the wellbeing of people living with cancer and their families, and to identify unmet needs and service gaps in the region.

Objectives and methods

The research partners comprised Blue Mountains Cancer Help (BMCH), Nepean-Blue Mountains Medicare Local (NBMML) and the University of Western Sydney (UWS). Nepean Cancer Care Centre (NCCC) became a collaborating site. Our project objectives were to describe the BMCH model and compare it with other community-based cancer support services; to investigate the experiences of BMCH clients, their carers and BMCH therapists; to explore local healthcare provider views on community-based cancer support services, BMCH in particular, and identify barriers and facilitators to recommending the service; and to make recommendations for future development of BMCH and community-based cancer support services.

Our research methods included a literature review to place the research into a broader context; a BMCH document analysis; and interviews, focus groups and surveys with BMCH members, general practitioners (GPs) and NCCC staff. Over 200 people shared their experiences and opinions—171 BMCH members (5 directors and staff, 20 therapists, 134 clients and 12 carers), 16 non-member carers, 9 GPs and 23 NCCC staff. To provide early feedback and help develop the final recommendations, NBMML organised a stakeholder workshop which was attended by over 40 clients, carers, therapists, GPs, allied health professionals and specialists.

Consumer members of the research team participated in developing the research plan, devising the survey, interview and focus group questions, interpreting the findings and framing the recommendations, and contributed to the report and conference presentations. Dedicated research staff collected and analysed the data and drafted the report, with input from the university researchers.

Results

The BMCH model has two key components: a service component and a funding component. BMCH is similar in its general philosophy, approach and the types of services offered to other Australian and international community-based cancer support services. The approach is one of wholistic care, acknowledging the need to address the physical, psychological, emotional and spiritual aspects of living with cancer. There is an emphasis on self-management and encouragement to make healthy dietary and lifestyle changes. BMCH activities are largely funded by two opportunity shops, supplemented by membership fees and money raised through special events and from sponsorships, donations and bequests. The organisation both supports and is supported by the local community. The local pool of skilled and dedicated therapists is an enormous asset. Volunteers, many of whom are former BMCH

clients or their relatives, make a major contribution. For some, their BMCH work is an opportunity to give back to the organisation and community.

Since its establishment in 2005, BMCH has developed into an effective, well-managed organisation, providing a range of services to people living with cancer and their families from a strong local community base. It has become a well-established entity in the Blue Mountains, with steadily increasing demand from people living in the Penrith area. However, the organisation's unique contribution in supporting the 'cancer journey' for clients and carers is not readily recognised by the general public or by health professionals, and it is often confused with the Cancer Council.

Benefits reported by BMCH clients and observed by others included connections and social support, information, access to a range of affordable therapies and programs, symptom relief and stress reduction, self-management skills and coping strategies, increased sense of control and confidence, and positive experiences. The wholistic approach, complementary to medical treatment, was widely appreciated. Carer benefits included support and information, as well as a reduced carer load. Some found their own quality of life was enhanced. Only five clients and one of the carers surveyed reported difficulties or problems; these were to do with distance from home, lack of after-hours groups, the predominance of clients with breast cancer and the small number of male clients.

Roughly half of the healthcare providers who participated in the study—GPs and NCCC staff—were not aware of BMCH. However, when the services and therapies were explained, most could see the potential benefits for their patients and were interested in obtaining more information.

In the BMCH and healthcare provider interviews, and at the stakeholder workshop, improved communication was identified as a key strategy for achieving an integrated model of care for people living with cancer. Communication between BMCH clients and healthcare providers about the use of BMCH services, and between BMCH therapists and healthcare providers, is important to ensure safe and effective treatment and to facilitate coordinated, client-centred care. Our research found an encouragingly high rate of disclosure of complementary therapy use to doctors compared with other Australian studies. All service provider participants—BMCH therapists, GPs and NCCC staff—expressed an interest in greater communication. NCCC staff wanted more information about BMCH and the specific therapies offered.

It is important that local and affordable support is readily available to people diagnosed with cancer and to their families and carers. Access to these services will also depend on healthcare providers being aware of such services and the benefits they offer so they can advise patients appropriately. Evaluations of cancer support services such as this are urgently needed in order to inform both healthcare providers and health service planners of the outcomes.

Recommendations

After nine years, BMCH has reached a critical stage. Organisational strengths include a supportive environment and the quality and commitment of the people involved. The challenge for the future is to grow the organisation through the identification of sustainable funding and infrastructure support whilst retaining the core elements of the model and keeping services affordable for all members. The following recommendations are based on the evaluation findings and discussions by stakeholders at the research workshop.

1. Use these evaluation findings to promote the benefits of community-based cancer support services and to advocate in the broader cancer environment for increased resources and funding to deliver safe, effective and wholistic services for all people living with cancer.
2. Improve awareness and knowledge of BMCH amongst local healthcare providers.
3. Develop strategies to improve communication between BMCH therapists and local healthcare providers and to support coordinated, client-centred care.
4. Develop strategies to promote BMCH to clients and carers by building brand awareness in the local community, including ways to engage more male clients and carers.
5. Promote consumer-driven health research and consumer involvement in all primary healthcare research and evaluation.

Introduction

Cancer is a leading cause of burden of disease in Australia and has a major impact on individuals, families and the health care system.¹ The incidence of cancer in Australia is increasing with an estimated 124,910 new cases in 2012 and that number set to rise to 150,000 by 2020.² At the same time, with earlier diagnosis and improved treatments, there has been an increase in survival rates with more than 60% of people with cancer surviving more than five years after diagnosis.³

To meet the needs of the rising number of people living with cancer, a range of cancer support services has emerged. In Australia, community-based services such as The Gawler Foundation⁴ in Victoria, Bloomhill Cancer Help⁵ in Queensland and Quest for Life⁶ in New South Wales have operated for twenty or more years and offer support services and complementary therapies. There has also been a growing trend in some countries to provide cancer support centres within hospitals. The SolarisCare Centre⁷ at the Charles Gardiner Hospital in Perth and the Olivia Newton-John Wellness Centre⁸ at the Austin Hospital in Melbourne are two well-known Australian examples. More recently, the Chris O'Brien Lifehouse⁹ has been established at Royal Prince Alfred Hospital in Sydney. These hospital-based centres aim to integrate conventional cancer treatments with those complementary therapies that have shown the greatest benefits, a practice referred to as integrative oncology.¹⁰

Blue Mountains Cancer Help Incorporated (BMCH) has been operating from an office in Katoomba since 2005. This not-for-profit, community-based cancer support service is based on the successful Bloomhill Cancer Help model, and is the only service of its kind in New South Wales. The aim of the organisation is to provide wholistic and integrated supportive care for people living with cancer and their families.

BMCH is self-funded through membership fees, donations and the proceeds of two opportunity shops. The fully trained and insured therapists offer a range of complementary therapeutic services to clients and the people who care for them. These are used alongside, and are not intended to replace, conventional medical treatments. All services are subsidised by the organisation. Since its inception BMCH has assisted over 600 clients. In the 2012–13 financial year alone, the organisation provided 2,916 services, including counselling sessions, at an estimated cost of \$72,900.

In addition to an evaluation of the BMCH model from the perspective of clients, carers and healthcare providers, the research reported here contributes to the general understanding of the ways in which community-based cancer support can improve the wellbeing of people living with cancer and their families. Despite increased recognition of the importance of such initiatives¹¹, there has been little research and there are few published papers on this topic.

Study Origins and Partners

This research grew from a discussion between Ms Diana Aspinall, Board Director of the Nepean-Blue Mountains Medicare Local (NBMML) and Ms Robyn Yates, Chief Executive Officer and founder of BMCH, following consultations with health consumers who identified what was needed for people with cancer. NBMML is dedicated to supporting the right health services for the Nepean and Blue Mountains communities by identifying the range of health service needs, as well as ways to bridge gaps in service provision. It covers four Local Government Areas (LGAs) to the west of Sydney—Blue Mountains,

Hawkesbury, Lithgow and Penrith—and has 138 general practices, 74 community pharmacies and 717 individual allied health professionals (physiotherapists, psychologists, social workers and so on).

Cancer is the leading cause of premature mortality in all four LGAs covered by the NBMML.¹² Community consultations involving over 500 consumers found a demand for support and complementary therapies by people diagnosed with cancer and their families. Previous attempts by BMCH to obtain additional resources to meet this identified need had been unsuccessful due to a lack of evidence to support the service model. Members were frustrated that the 34 recommendations made in the 2005 Senate Committee Report into services and treatment options for people with cancer had not been fully implemented, directly affected funding and resources available for cancer support services.¹¹

The NBMML Board agreed to fund the project under its Consumer and Community Engagement Strategy, in keeping with its broad commitment to consumer-driven health research. The University of Western (UWS) Department of General Practice was engaged to provide academic support.

BMCH, NBMML and UWS were the three original research partners. Later, Nepean Cancer Care Centre (NCCC) joined the study as a collaborating site. NCCC is the main referral and treatment centre for cancer clients living in the Blue Mountains and Penrith areas. It is located within the grounds of the Nepean Hospital in Penrith and provides surgical, radiotherapy, chemotherapy and palliative services, as well as support from psychiatrists, psychologists, social workers and allied health workers and a lymphoedema management service.

Research Objectives and Questions

The objectives of this evaluation were to:

1. Describe the BMCH model;
2. Describe other models of community-based cancer support services;
3. Investigate the experiences of clients, carers and therapists working with BMCH;
4. Explore General Practitioner (GP) views on community-based cancer support services, in particular BMCH, and identify barriers and facilitators to recommending such a service;
5. Explore NCCC staff views on community-based cancer support services, in particular BMCH, and identify barriers and facilitators to recommending such a service; and
6. Make recommendations for the future development of BMCH and cancer support services in the region.

The research questions comprised:

1. What is the BMCH model and how does this compare to other similar services?
2. What is the underlying program rationale or logic? How does it work?
3. What are the main benefits experienced by BMCH clients and carers and observed by others?
4. What are the major strengths and challenges facing BMCH?
5. How do primary healthcare providers view BMCH services? What concerns do they have?
6. How do NCCC staff view BMCH services? What concerns do they have?
7. What are the main facilitators and barriers to healthcare providers and NCCC staff recommending BMCH, and how can the barriers be overcome?

Approach and Methods

Consumer-led Research

As noted above, the need for this project was identified through consumer and community consultations. Consumers took an active role at every level and every stage. Consumers were invited to join the steering committee, which had a consumer as chair, as well as the various working groups. Consumer members participated in design and development of the research plan, development of the survey, interview and focus group questions, interpretation of the findings and development of the recommendations, and contributed to the report and conference presentations. Dedicated research staff collected and analysed the data and drafted the report, with input from the university researchers.

Methods

The research included a literature review (led by Dr Louise McDonnell), a BMCH document analysis (led by Dr Ilse Blignault) and interviews, focus groups and surveys with BMCH members, GPs and NCCC staff (led by Ms Robin Thomas).

The **literature review** allowed us to place the research into a broader context. A narrative approach was used to describe community-based cancer support services operating internationally and in Australia. The search was confined to publications since 2000 and used the following databases: MEDLINE, Cochrane and Scopus. In addition, an internet search was made of relevant websites including Google Scholar, the Australian Department of Health and Ageing, Cancer Council Australia and the state and territory Cancer Councils. Finally, information on other cancer support organisations around Australia was sourced by BMCH staff. The **document analysis** included BMCH annual reports and volunteer handbook, service brochures, fliers for specific events, letters, and media reports.

The study was advertised through the BMCH newsletter, website and fliers available at the BMCH office. At the start of the research, five of the **BMCH directors and staff** were interviewed to gain an overview of the organisation's history and achievements and its current strengths and challenges. The hour-long semi-structured interviews were audiotaped and transcribed for analysis.

BMCH clients who had accessed a service or attended a support group over the previous 12 months were sent a personal letter of invitation along with a participant information sheet, a 4-page questionnaire and reply-paid envelope. Questions covered demographic data; experiences, benefits from and problems with BMCH services; and whether they had discussed their use of BMCH with healthcare providers. An online version of the questionnaire was also offered via Survey Monkey but few clients took up this option. Follow-up letters were sent three weeks later, and follow-up phone calls were made to those who had not responded after another three weeks.

Clients were also invited to attend one of three focus groups: one for men, one for women and one for clients who had participated in art therapy groups. Topics for discussion included the best aspects of BMCH; the value of structured group support; challenges associated with accessing appropriate services; talking about involvement with BMCH with their doctors; and suggestions for improving cancer services and support in the Blue Mountains and Penrith areas. The discussions, which lasted about 1½ hours, were audiotaped and transcribed for analysis. Written consent was obtained from participants beforehand.

In addition to completing their own survey, clients were asked to invite their **carer** or support person—spouse/partner, family member or friend—to take part in a separate survey which was included with the client package. After demographic data, the 3-page questionnaire asked carers about the benefits from BMCH involvement experienced by the client and by them personally. Carers who were BMCH members themselves were asked extra questions about their use of BMCH services, including benefits and problems.

BMCH therapists were also invited to take part. Following a telephone call explaining the evaluation, they were sent a participation information sheet together with a 3-page questionnaire and reply-paid envelope. Questions assessed their experience of working with BMCH, including their need for support and communication with other healthcare providers.

GPs were informed of the study through an advertisement in the NBMML Newsletter. All GPs within the NBMML boundaries were sent an invitation to participate in a face-to-face interview about community-based cancer support services. Written consent was obtained prior to the interviews, which were audio-taped and transcribed.

NCCC staff received an invitation to participate in an online survey (Survey Monkey) via the internal email system. The questions addressed such issues as awareness of national, state and local cancer support services including BMCH, interest in recommending patients to BMCH, and suggestions for improving cancer services and support in the Blue Mountains and Penrith areas. Follow-up emails were sent three weeks later.

Analysis was undertaken as the different sets of data were collected. With the exception of the demographic items, the survey questions for clients, carers and therapists were predominantly open-ended. Responses were systematically coded and tabulated, then studied and grouped thematically for further analysis by the four core members of the research team. Most of survey questions for NCCC staff, on the other hand, had pre-coded answers. In such cases, frequency tables were constructed. Interview and focus group transcripts were reviewed by the four researchers and analysed according to the research questions.

The research design was strengthened by triangulation of data gathered using a variety of methods and sourced from a range of informants. To provide some early feedback and help develop the recommendations, NBMML organised an evening workshop for stakeholders where the key findings were presented and discussed. The event was attended by over 40 clients, carers, therapists, GPs, allied health professionals and specialists.

Ethics Approval

The study received ethics approval from the Human Research Ethics Committee of the Nepean Blue Mountains Local Health District: study 13/81 – LNR/13/Nepean/141. The ethics approval was ratified by the University of Western Sydney HREC: reference H10543.

Results

This section presents a summary of the results of the literature review, followed by a description of the BMCH model as it currently operates, and then the results of the surveys, interviews and focus groups with clients, carers, therapists, GPs and NCCC staff. Findings related to communication and connections and to organisational strengths and challenges are covered separately. The full literature review (12 pages) is included in a separate appendix which is available from NBMML or BMCH on request.

Literature Review

In Australia, community-based cancer support services have been operating for several decades. Excluding BMCH, seven currently operating services were identified, five of which have been operating for more than 20 years. Similarly, most international community-based cancer support services have been operating since the 1990s.

The international and Australian community-based programs have many similarities. Almost universally, the approach is one of wholistic care, acknowledging that cancer affects the whole person and the need to address the physical, psychological, emotional and spiritual aspects of living with cancer. Many of the programs emphasise the concept of healing, not necessarily to attain a cure, but more to heal, physically, psychologically and spiritually. There is an emphasis on self-management and encouragement to make healthy dietary and lifestyle changes. There are also similarities in the types of services provided. Most of the centres offer a range of complementary therapies and support groups. Many offer a drop-in centre where clients can access information, counselling and a library. In addition, many offer a variety of workshops and retreats.

Funding models vary across countries and information on funding sources was not available for all services. None of the services in Australia receive significant government funding, relying instead on donations, membership and course fees. Bloomhill Cancer Help funds its services through the proceeds of seven opportunity shops. In the United Kingdom, most centres are run by charities with minimal or no government funding.

Blue Mountains Cancer Help Model

The model presented here is based on the BMCH document analysis and information gathered in interviews with BMCH directors and staff members. Table 1 below, which breaks the model down into its separate elements, was also informed by data collected from clients, carers and therapists.

BMCH is a non-profit, non-denominational charitable organisation committed to helping cancer clients and their families retain their sense of control and balance through innovative, integrated and wholistic therapies and education, while giving hope for challenging circumstances.¹³ The organisation has a strong local community focus; both supporting and being supported by the local community. The office is located in Katoomba, with two opportunity shops in Katoomba and Penrith. The elected board of directors (all Blue Mountains residents and all volunteers) meets monthly.

The 'BMCH model', which was based on the 'Bloomhill model', has two key components. The service component entails the provision of emotional, social and practical support for people with cancer and their families from people who have had similar experiences or understand deeply what they are going

through. The funding component involves the generation of income for the organisation from the two opportunity shops. This is supplemented by membership fees and funds raised through special events and from sponsorships, donations and bequests.

BMCH people include a small paid staff of four, over 30 qualified and experienced therapists and over 70 trained volunteers, as well as client and carer members. The target group includes persons diagnosed with all types of cancer and their families. Services are available for people both during and after medical treatment. Complementary therapies are not proposed to replace medical interventions but are used to alleviate negative aspects of cancer treatment and minimise side effects such as lymphoedema.¹³

Values of compassion and care are central to the organisation. Staff and therapists work in a holistic way with the focus on wellness and maintaining good health. All clients are assessed by a registered nurse who provides information about the complementary therapies and other support available and may recommend a particular therapy or group. They are offered social, emotional and practical support on an individual and group basis; subsidised complementary therapies and counselling; and education and information. The range of services includes massage, lymphoedema management, acupuncture, reiki, reflexology, Qigong, art therapy, group therapy, counselling; and a 12-week 'Living Well with Cancer' program. (See glossary at end of report for service descriptions.) Clients are encouraged to make their own choices about what they need and when. Self-help is encouraged and there is acknowledgement of spirituality and 'bigger life questions'. BMCH also operates a book/CD/DVD library and a wig library. Overall, the system is flexible and responsive, rather than rigid and prescriptive. Members can come in or phone to talk at any time, knowing that confidentiality is assured.

While the 'Op Shops' are mainly there to finance services, they also provide a broader community benefit, especially to the socially disadvantaged community members who are able to obtain good quality clothes and household goods cheaply. Some people first learn about BMCH there and become clients. Ex-clients and carers give back to BMCH and the community through donations and assisting in the shops as volunteers. The work simultaneously provides individuals with sense a of purpose and brings the community together.

The way in which the BMCH model works is displayed in Table 1, which shows the relationship between the different inputs, activities, processes and outcomes. At the very top of the table are the core values and principles of the organisation; then the resources at the organisation's disposal, including the people, culture and physical facilities; then the various activities that take place, including service provision, community awareness and fund raising; then the mechanisms or processes that lead to change; and, finally, the individual and community outcomes.

Table 1. How the BMCH Model Works

Values and Principles	<p>Compassion, care, confidentiality, respect Wholistic – Considering the whole person: mind, body and spirit Complementary – “Therapies are not intended to replace medical interventions” Community-based – “With the community working together we can achieve anything”</p>			
Resources	<p>Friendly, welcoming physical environment Caring, responsive organisational culture Strong leadership and effective governance Committed membership including board members, professional staff, qualified therapists and trained volunteers Deep understanding of experience of living with cancer Time and flexibility – “More time than GPs, that’s the bottom line.” Book/CD/DVD library and wig library Opportunity shops Community goodwill and support – handmade blankets, quilts and other donations, bequests, event sponsorship</p>			
Activities	<p>Initial assessment</p> <p>Ongoing encouragement</p>	<p>Support groups ‘Living Well with Cancer’ program Sponsorship to attend other courses, e.g. Quest for Life Counselling Art therapy group Complementary therapies</p> <ul style="list-style-type: none"> • Mind-body techniques • Body-based practices 	<p>Opportunity shops Fundraising, e.g. ArtyBra Community cancer awareness, e.g. Purple Tie Week Community education, e.g. grief workshops and Sunshine Day Newsletter Transport assistance</p>	
Change Mechanisms	<p>Connections – realising that you are not alone, being able to freely express emotions, fears and hopes to others outside immediate family who understand what you are going through Learning – that you can take responsibility for your health and your body Therapeutic benefits – from affordable, locally available services Peer support – from people who have gone through same thing Community support – from broader community, e.g. gift of blanket Spiritual healing Empowerment</p>			
Individual Outcomes	<p>Clients</p> <p>Enhanced quality of life Sense of control & balance Sense of belonging & community Wholistic wellbeing Increased knowledge New coping skills Increased confidence Improved relationships New friends/less alone & isolated Access to support as needed Less pain & other symptoms Relaxation Less fear of cancer & death Ease with new body & self Joy, hope & other positive emotions New meaning in life</p>	<p>Family and carers</p> <p>Knowledge that loved one is supported Reduced carer burden Access to own support as needed New friends Changed life priorities Supported in grief & loss</p>	<p>Therapists</p> <p>Deep understanding of cancer journey Wider view of life Appreciation of individual differences Honoured, privileged, humbled & inspired Opportunity to practice with like-minded people Skills & experience valued Therapist network & supervision Opportunity to give back to community Personal & professional growth</p>	<p>Staff and volunteers</p> <p>Satisfaction from helping others Opportunity to give back to BMCH & broader community Sense of purpose Wholistic wellbeing</p>
Community Outcomes	<p>Supportive environment – “A lot of people who work at the op shops say it’s almost like a community service.” Local collaborations and partnerships that support community health and wellbeing.</p>			

Client Perspective

“It helped considerably with the effects of chemotherapy and, I believe, has greatly improved my wellbeing for the past 3½ years.” (BMCH Client)

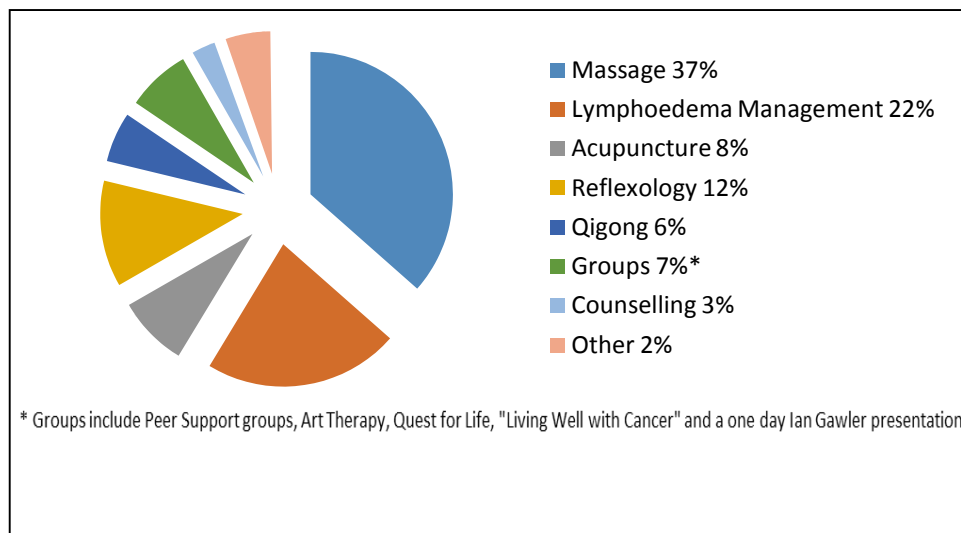
A total of 211 surveys were mailed to BMCH clients at their home address and 116 were returned. Two forms were incorrectly completed, resulting in 114 valid forms and a response rate of 54%. Collectively, these 114 respondents accounted for over three quarters (78%) of total services provided by BMCH in the preceding 12 months, i.e. they included the most involved client members.

The client respondents included 104 (91%) women and 10 (9%) men. Fifty per cent fell into the 46–64 age bracket and 42% into the 65 or older age bracket, with 8% aged 18–45. Just over half (54%) lived within thirty kilometres of BMCH.

The majority of clients (74%) had been diagnosed with breast cancer, either alone or in combination with another cancer. Eight (6%) clients had ovarian cancer, alone or in combination, 4% melanoma and 4% prostate cancer. The remaining 23% had other types of cancer. Most (57%) joined BMCH within 1–5 years of their diagnosis and another 29% within 6–20 years. There were also some clients who joined within a year of their diagnosis (5%) or more than 20 years afterwards (9%)

Clients were asked about the types of services they had used, and the approximate number of sessions, in the last 12 months. In order of frequency, the results were massage (37%), lymphoedema massage (22%), reflexology (12%), acupuncture (8%), group therapy (7%), Qigong (6%), Bowen Therapy (3%), counselling (3%), and other (2%) (see also Figure 1).

Figure 1. Number of Sessions Used by BMCH Clients by Service Type



In terms of benefits, clients reported that they had experienced not only physical wellness and psychological wellbeing but also obtained information from both individual and group therapies. Several also mentioned benefits of a spiritual nature. Individual therapies appeared to contribute more to symptom relief and group therapies to improved social connection, but there was considerable crossover (see Table 2). Just knowing that BMCH existed was reassuring for some people: *“Just knowing that you are there, that I can ring at any time and I can speak to someone is a great comfort.”*

Only five (4%) clients reported any difficulties or problems; these were to do with distance from home, lack of after-hours groups, the predominance of clients with breast cancer and the small number of male clients. A sense of non-inclusion sometimes experienced by women with other cancers and by men was also raised in the focus groups. The fact that BMCH services were subsidised was greatly appreciated, with 94% of clients describing them as affordable.

Clients also expressed concern about the impact of the cancer diagnosis on their family, particularly children, and their need for support too. This issue was also raised at the stakeholder workshop.

Table 2. Client Opinions on Benefits of BMCH Services

Therapies	Symptom Relief	Relaxation	Wellness	Information	Social Aspect	Spiritual Aspect	Illustrative Quotes
Massage	✓	✓	✓	✓	✓		“Softening of scar tissue and reduction of tightness of muscles. Relaxation and time out when stressed.” “Relaxation, stress relief, easing of stiff muscles ... Aided movement of the arm and shoulder. Less headaches from shoulder and neck pain.”
Lymphoedema Management	✓	✓	✓	✓			“Reduced swelling and therapist offered useful advice on managing lymphoedema.” “Lymphoedema drainage keeps my arm feeling comfortable and helps with fluid build-up.”
Acupuncture	✓	✓	✓				“Helps relieve anxiety and nausea from chemotherapy.” “Helped considerably with the effects of chemotherapy and ... has greatly improved my wellbeing ...”
Reflexology	✓	✓	✓	✓			“Significant improvement in neuropathy/swelling due to chemotherapy side effects.” “It gives me relaxation, stimulates circulation, massages internal organs and detoxifies.”
Qigong	✓	✓	✓		✓		“Growth of calm and inner strength. Helps with anxiety and insomnia.” “It helped to be welcomed and part of a group with common experience. I found it emotionally and physically grounding.”
Art Therapy Group	✓		✓		✓	✓	“Supportive group allowed exploration of fears, anxieties, i.e. challenging part of illness.” “I could discuss painful matters and have support, and most importantly, guidance.”
Peer Support Group			✓	✓	✓		“Reducing loneliness, having a cry and a laugh together.” “I attended and off-loaded my fears, and felt supported and understood.” “Beneficial to meet and talk with others going through the same thing.”
Counselling	✓	✓	✓	✓			“Helped with anxiety about my own symptoms and about stress of carer role with ageing partner.” “Felt I left unburdened by issues that had been weighing on me.”
Living Well		✓	✓	✓	✓		“Was enlightening and inspiring. Provided very practical relaxation exercises and easy to follow meditation techniques.” “Helped me feel more self-confident to deal with cancer and I found [the group leaders’] support fantastic.”
Reiki	✓	✓	✓			✓	“Helped me relax and rest well for several days following treatment. Also felt calm and confident in facing challenges.” “Relief of symptoms in gut, back, shoulders – all over tension and anxiety, insomnia.”
Bowen Therapy	✓	✓	✓				“It helped my overall body to be balanced.” “Helped promote good sleep.”

Carer Perspective

“I like it that someone else is having input with the person I have been caring for; I am released ...” (Carer)

Twenty-eight carers, including 15 men and 13 women, returned the carers’ survey. Of these, 12 (43%) were BMCH carer members, which meant that they were eligible for BMCH services themselves, and 16 (57%) were non-members. On the whole, the carers were younger than the clients, with people in the 46–64 age bracket making up 57% of respondents and those aged 65 or over making up 37%. Three (11%) were aged 18–45. As with the clients, the majority of carers (82%) lived in the upper Blue Mountains.

When asked about the benefits experienced by the person they cared for through involvement with BMCH, the carers’ responses were similar to those reported by the clients surveyed. The carers were also asked what they had personally gained from BMCH. Carer benefits included therapeutic benefits for those who were BMCH members and had accessed therapies or counselling, as well as a lifting of the responsibility for providing support for a family member or close friend with cancer. Some found their own quality of life was enhanced (see Table 3). Only one of the 28 carers reported a problem; this was related to travel and distance.

Table 3. Carer Opinions on Personal Benefits of Involvement with BMCH

Carer Benefit	Illustrative Quotes
Support	<ul style="list-style-type: none"> • “Excellent support ... emotional, financial and medical.” • “A great sense of support, knowing there was a ‘go to’ organisation that would understand.”
Information	<ul style="list-style-type: none"> • “Good information on what to expect and that what she is experiencing is normal for her condition.”
Relief from Load	<ul style="list-style-type: none"> • “Peace of mind that we were actively adding management strategies to her treatment.” • “Reduced the pressure of having to have all the answers and being my partner’s only sounding board.” • “Having opportunities to be social has taken the pressure off [me] to facilitate these experiences. Our relationship can focus on mother–daughter ...”
Quality of Life	<ul style="list-style-type: none"> • “The people and therapists I have met through BMCH have been affirming, supportive and life-enhancing – this has been encouraging for me.” • “Involvement with people undergoing a major health crisis has changed my lifestyle and my priorities as to what is important in life.”

Therapist Perspective

“Our clients find things like connection, information, role models, hope and support. They find a place to tell their stories, to be real, to be supported physically, emotionally and spiritually. They find a community to be part of.” (BMCH Therapist)

Therapist surveys were mailed to 26 therapists who had regularly seen BMCH clients during the 12 months prior to the evaluation and 20 responded, giving a participation rate of 77%. All were qualified within their speciality: 12 held certificates, 6 held diplomas, and 6 had bachelor degrees. Their length of practice ranged from one year to more than 30 years, with a median of 8 years.

The therapists reported a range of benefits to clients as a result of their involvement with BMCH, including increased connections and social support and access to affordable, wholistic care and complementary therapies (Table 4).

Table 4. Therapist Opinions on Client Benefits of Involvement with BMCH

Perceived Client Benefit	Illustrative Quotes
Connection/Support	<ul style="list-style-type: none"> • “[BMCH] offers a heart connection along with solid information and a way to be creatively involved” • “Dignity, respect, answers, comfort, relief, friendship, support, self-esteem, belonging.”
Wholistic approach	<ul style="list-style-type: none"> • “A local wholistic approach to complement their hospital care during pre and post medical/hospital treatments. “ • “Access, at affordable cost, to resources they may not otherwise have considered.”
Therapeutic	<ul style="list-style-type: none"> • “Relief of their physical and emotional suffering and relief of side effects of cancer treatment drugs.” • “Low-cost therapies that can assist in many and varied ways.”
Information	<ul style="list-style-type: none"> • “A first hand understanding of how complementary medicine can support them through all phases of the diagnosis, treatment and recovery.” • “Referral to organisations that can help.”
Life Enhancing	<ul style="list-style-type: none"> • “Greater resilience, both physically and mentally, to their experience and treatment of cancer.”

The therapists themselves gained a lot from interaction with the BMCH clients, both personally and professionally. Personal gains included a sense of pride in assisting others, a sense of admiration for clients and a sense of community involvement. Over time, they developed their own skills and networks and increased their clinical knowledge about cancer (Table 5).

Table 5. Therapist Opinions on Gains for Themselves

Therapist Benefit	Illustrative Quotes
Honour/Privilege	<ul style="list-style-type: none"> • “The opportunity to work with people at a very difficult time in their lives. It is an honour to sit with people as they explore their hopes and fears.” • “The privilege and rewards that come with treating those trying to cope physically, emotionally and spiritually with a life-threatening illness.”
Giving Back	<ul style="list-style-type: none"> • “The opportunity to give back after all the help I have had.”
Understanding, Skills & Experience	<ul style="list-style-type: none"> • “Deeper understanding of issues related to life-threatening illness and its impact, including grief.” • “Greater appreciation of the scope of issues people with cancer experience that in turn require me to reflect and research how best to deliver [therapy] for their needs.” • “Experience with a wide variety of client issues that challenge my skills and help expand my knowledge and professional network.”

General Practitioner Perspective

The GPs interviewed recognised several potential benefits of the BMCH service model for patients with cancer. Access to complementary therapies was seen as a positive feature, with particular mention of the benefits flowing from massage and human touch. The social support and connection with others going through a similar experience was also seen as a major benefit.

Nine GPs were interviewed, five female GPs and four males. Four GPs practised in the Blue Mountains and five in the Nepean area (Penrith to St Marys). Their length of time in general practice ranged from 1½ to 43 years. Of the nine, two were providing complementary therapies to their cancer patients; one was a qualified naturopath and the other was a qualified hypnotherapist. A third GP described herself as an “integrative medical practitioner”.

Five of the nine GPs said that they were aware of BMCH and understood that BMCH treatments were offered alongside usual medical treatments, not as an alternative. All five had recommended or provided information about BMCH to their patients. When the four GPs who were not aware of BMCH were provided with information about the organisation, all but one (who was concerned about the distance to travel and cost) agreed the services offered could be of value to their patients.

Perceived benefits included access to complementary therapies, provided at home on occasion, social support and connection with others going through a similar experience. Some GPs thought that clients could gain from the positive outlook provided by BMCH, and a feeling of increased control over the body and mind. Others valued BMCH’s education programs and professional support; knowing that information and support was available to help cope with the challenges of living with cancer if required.

All the GPs spoke at some point about patient safety; they agreed that community-based cancer support services should be provided by qualified therapists and used alongside mainstream cancer

treatments. One GP was concerned about the possible duplication of services, particularly in relation to oncology massage services. GPs whose practices were located in more socioeconomically disadvantaged suburbs were concerned about any cost to their patients.

Summary of Client Benefits

Table 6 summarises the benefits experienced by BMCH clients from the perspective of clients, carers, therapists and GPs. The data are drawn from the survey questionnaires, focus groups and interview transcripts. An empty cell does not imply that the benefit did not exist; merely that it was not asked of, or reported by, the particular group of informants when describing client benefits. Overall, there was strong agreement about the range of benefits to clients.

Table 6. Summary of Reported and Observed Benefits to BMCH Clients

Benefit	Clients	Carers	Therapists	GPs
Social support and connection	✓	✓	✓	✓
Access to a range of services	✓	✓	✓	✓
Wholistic approach	✓		✓	✓
Home visits	✓			✓
Physical and mental wellbeing	✓	✓	✓	
Symptom relief and stress reduction	✓	✓	✓	✓
Self-management skills and coping strategies	✓	✓		✓
Sense of control and confidence	✓	✓		✓
Positive experiences/life enhancing	✓	✓	✓	✓
Affordability – subsidised services and 'Quest for Life'	✓	✓	✓	
Information	✓	✓	✓	✓
Complementary to medical treatment	✓	✓	✓	✓

Nepean Cancer Care Centre Perspective

A total of 23 people at the NCCC participated in the survey out of 90 staff, giving a 26% response rate. Six medical specialists took part, six nurses, eight allied health practitioners and three others. Almost two-thirds (65%) of the staff surveyed had worked at the centre for five years or more.

Fifty per cent of the respondents were not aware of the existence of BMCH. Of those who were aware, 25% had recommended BMCH to their patients. However, potential for increasing recommendations exists with 64% reporting an interest in learning more about BMCH. Eighty-five per cent stated that providing information on the types of therapies provided by BMCH would make them more likely to recommend BMCH to their patients. Information regarding the qualifications of the therapists would also make NCCC staff more likely to recommend patients. Brochures as well as presentations and seminars about BMCH were thought to be the best means of conveying this information.

When asked what services community-based cancer support centres should offer, 90% of NCCC staff believed peer support should be offered. This was followed by information for clients (75%), exercise classes (65%), and counselling (50%).

NCCC staff were asked their level of interest in recommending specific services currently offered by BMCH. Seventy eight percent reported an interest in recommending patients for support group services, 59% for meditation and 56% for information (see table 7).

Table 7. NCCC Staff Interest in Recommending BMCH Services

Therapy	Not Interested	Unsure	Interested
Support groups (n=18)*	2 (11%)	2 (11%)	14 (78%)
Meditation (n=17)	3 (18%)	4 (24%)	10 (59%)
Information resources (n=18)	2 (11%)	6 (33%)	10 (56%)
Individual/family counselling (n=16)	3 (19%)	6 (38%)	7 (44%)
Lymphoedema management (n=18)	8 (44%)	2 (11%)	8 (44%)
Reiki (n=16)	8 (50%)	3 (19%)	5 (31%)
Reflexology (n=16)	8 (53%)	3 (20%)	4 (27%)
Oncology massage (n=16)	4 (25%)	8 (50%)	4 (25%)
Living Well Program (n=18)	7 (44%)	5 (31%)	4 (25%)
Acupuncture (n=15)	6 (40%)	6 (40%)	3 (20%)

* n indicates the number of NCCC survey respondents who answered that particular question.

Communication and Connections

Better promotion of BMCH and its potential benefits to people living with cancer was identified as an important means of facilitating uptake of BMCH services by all groups of study participants—those involved with BMCH, GPs and NCCC staff. In stakeholder discussions at the research workshop, improved communication was suggested as one of the key strategies for achieving an integrated and joined-up model of care without fragmentation or duplication.

Communication between clients and healthcare providers

In the client survey, respondents were asked if they had discussed their use of the BMCH services, including complementary therapies, with their GP or specialist and, if so, if they were supportive. Open-text responses were coded into ‘supportive’, ‘dismissive’ or ‘no comment’. Seventy-three per cent of clients had discussed the use of BMCH services with their GP and 61% with their specialist. In the majority of cases the doctors were supportive—82% for GPs and 76% for specialists. The following comments by clients are illustrative:

“My GP is glad that I am taking care of myself and being surrounded by helpful people.”

“Oncologist stated that improving wellbeing and health during chemo and surgery is very important to having a good outcome”.

Only 3% clients reported a dismissive response from their GP, while 8% reported that the specialist was dismissive. For example:

“The GP appeared totally disinterested.”

“My breast surgeon was very dismissive and couldn't see the benefits of massage.”

Communication between health professionals

None of the therapists surveyed had communicated with a client's GP. However, 60% said such contact would be useful. The GPs interviewed also expressed willingness to communicate with therapists. Communication was cited most frequently by NCCC staff as a proposed means of working more closely in partnership with BMCH, followed by additional information on the service.

Connections with other services

BMCH is very well connected in local community and has organisational partnerships with the Palliative Support Service in Lawson, the Nepean/Blue Mountains Prostate Cancer Support Group, the Bosom Buddies Breast Cancer Support Group, and the Pendragons Abreast Dragon Boating Group. It also has strong connections with other similar community-based cancer support services organisations such as Bloomhill Cancer Help, the Gawler Foundation and the Quest for Life Foundation. The BMCH Chief Executive Officer and her counterparts communicate regularly, sharing ideas and keeping their programs up to date.

Organisational Strengths and Challenges

“It's not just a job.” (BMCH staff member)

BMCH is a local community organisation which has grown from grass roots. Despite the large number of volunteers and a growing client base, the organisation retains an intimate environment. There is a welcoming approach to new members which is assisted by the affordable cost.

The Blue Mountains location was identified in the initial interviews as a major strength. People move to the Blue Mountains for the natural environment and the local community has an interest in health and wellness which is reflected in the relatively large number of complementary therapists practising in the area. The Blue Mountains is also well resourced with several community health centres and a community palliative care team. Another strength identified was the quality and commitment of the members. Many of the volunteers are ex-clients who have benefitted from BMCH services and seek to give back. They also bring the personal knowledge and understanding that comes with having experienced cancer in their own lives. The therapists have a strong belief in BMCH and are committed to it in the long term. As cancer affects people from all walks of life, people with a variety of skills are able to bring them to BMCH.

One of the challenges for BMCH is to build understanding about the organisation and the role community-based cancer support services, including complementary therapies, can play in helping people living with cancer and convey this to health professionals and the broader community.

Continuing collaboration with community organisations and increased integration with health services was seen as priority by BMCH directors.

As with any other organisation in the not-for-profit sector, ensuring sufficient resources is a continual struggle. Many people mistakenly assume that BMCH is funded by the Cancer Council and that it is well resourced. In fact, BMCH gets the majority of its income the proceeds from two opportunity shops and is under-resourced financially. Increasing fees to stay financially viable carries the risk of reducing affordability for clients. BMCH is heavily reliant on the skills and goodwill of volunteers, thus finding and training new volunteers is an ongoing activity. The BMCH board requires an injection of new, and younger, members to manage the organisation into the future. The organisation requires larger office premises.

Recent expansion of the organisation into the Nepean region provides an avenue for growth, but this must be achieved without damage to the successful BMCH model and without reducing services to the Blue Mountains region—BMCH's home. In particular, growth must be achieved whilst keeping the focus on the local community and retaining the personal touch.

Discussion

Study Limitations

Only nine GPs were interviewed and the response rate for the NCCC online survey was only 26%.

Summary of Findings

The BMCH model has two key components: a service component and a funding component. BMCH is similar in its general philosophy, approach and the types of services offered to other Australian and international community-based cancer support services. The approach is one of wholistic care, acknowledging the need to address the physical, psychological, emotional and spiritual aspects of living with cancer. There is an emphasis on self-management and encouragement to make healthy dietary and lifestyle changes. BMCH activities are largely funded from the proceeds of two opportunity shops, supplemented by membership fees and money raised through special events and from sponsorships, donations and bequests. The organisation both supports and is supported by the local community. The pool of skilled and dedicated therapists is an enormous asset. Volunteers, many of whom are former BMCH clients or their relatives, make a major contribution. For some, their BMCH work is an opportunity to give back to the organisation and community.

Since its establishment in 2005, BMCH has developed into an effective, well-managed organisation, providing a range of services to people living with cancer and their families from a strong local community base. It has become a well-established entity in the Blue Mountains, with steadily increasing demand from people living in the Penrith LGA. However, the organisation's unique contribution in supporting the 'cancer journey' for clients and carers is not readily recognised by the general public or health professionals, and it is often confused with the Cancer Council.

Benefits reported by the BMCH clients and observed by others included connections and social support, information, access to a range of affordable therapies and programs, symptom relief and stress reduction, self-management skills and coping strategies, increased sense of control and confidence, and positive experiences. The wholistic approach, complementary to medical treatment was widely appreciated. Carer benefits included support and information, as well as a reduced carer load. Some found their own quality of life was enhanced. Only five clients and one of the carers surveyed reported difficulties or problems; these were to do with distance from home, lack of after-hours groups, the predominance of clients with breast cancer and the small number of male clients.

Roughly half of the healthcare providers who participated in the study were not aware of BMCH. However, when the BMCH services were explained, most could see the potential benefits for their patients and were interested in obtaining more information.

In the BMCH and healthcare provider interviews and at the research workshop, improved communication was identified as a key strategy for achieving an integrated model of care for people living with cancer with no fragmentation or duplication. This point is of relevance to communication between clients and healthcare providers and to communication between health professionals themselves. Communication between BMCH clients and healthcare providers about the use of BMCH services, and between BMCH therapists and healthcare providers, is important to ensure safe and effective treatment and to facilitate coordinated, client-centred care.

Our research found an encouragingly high rate of disclosure of complementary therapy use to doctors compared with other Australian studies.¹⁴ BMCH therapists, GPs and NCCC staff expressed an interest in greater communication. NCCC staff wanted more information about BMCH. The Australian medical community is becoming more accepting of a wholistic approach to cancer support and complementary therapies.¹⁴ This trend is reflected in the number of integrative oncology and survivorship programs which have opened in major Australian cancer treatment centres in recent years. While the growth in hospital-based cancer support services is welcomed, the equally pressing need for community-based services should not be overlooked. Most of those established in Australia to date are dependent on donations and minimal client fees, as well as the generosity of their largely volunteer workforce, to provide much sought after services.

In view of the increasing rates of cancer diagnosis and survival and our ageing population, it is important that affordable cancer support is readily available to people living with cancer and their families and carers. Access to these services will also depend on healthcare providers being aware of such services and the benefits they offer so they can advise their clients appropriately. There is clearly a great need for evaluations of community-based cancer support services such as this one in order to inform both health care planners and providers of the individual and community outcomes.

A number of issues for further research and quality improvement were identified during this project. These included:

- What is required to address the isolation that may be felt by a person with an uncommon or rare cancer diagnosis;
- The needs of men living with cancer and their carers, and the barriers that prevent men accessing cancer support services;
- The long-term needs for support, information and services by cancer survivors who are now living longer, including the impact of a cancer diagnosis on career pathways, employment and future financial management issues;
- Demonstrating the benefits of complementary therapies and psychosocial interventions on quality of life using standardised measures, as well as investigating their cost effectiveness.

Future Directions and Recommendations

After nine years, BMCH has reached a critical stage. The challenge for the future is to grow the organisation through the identification of sustainable funding and infrastructure support whilst retaining the core elements of model and keeping services affordable for all members. The recommendations below are based on the evaluation findings and discussions by stakeholders at the research workshop. Several, particularly those that pertain to BMCH internal operations, are already underway. Others will require coordinated effort by different groups of stakeholders.

1. ***Use these evaluation findings to promote the benefits of community-based cancer support services and to advocate in the broader cancer environment for increased resources and funding to deliver safe, effective and wholistic services for all people living with cancer.***

There is an urgent need for increased awareness and recognition of the benefits of attending community-based cancer support services such as BMCH. In particular, acknowledging the benefits of a holistic approach that promotes health and wellbeing during and after cancer treatment with focus on self-management and healthy lifestyle. Strategic partnerships with non-government organisations, government departments and agencies and the private sector at the local, state and national levels will strengthen advocacy efforts.

2. *Improve awareness and knowledge of the BMCH service amongst local healthcare providers.*

Roughly half of the primary and specialist healthcare providers who participated in this study were unaware of the BMCH, however after an explanation most could see the potential benefits for their patients and were interested in obtaining more information. General information should emphasise the benefits to clients and carers of social connectedness, education and increased self-management skills. Detailed information about the different complementary therapies and the evidence supporting their use in cancer support would assist in addressing concerns about safety and efficacy and increase the likelihood of recommendations to BMCH.

As the local cancer treatment, NCCC is a crucial source of information for many patients and their families, particularly in the early stages after diagnosis. Developing a relationship with NCCC so that clinicians are more confident in recommending BMCH to patients would increase awareness of the service. Information about BMCH should also be disseminated in general practices and other health and community settings in the region.

3. *Develop strategies to improve communication between BMCH therapists and local healthcare providers and to support coordinated, client-centred care.*

Good communication between health care providers is essential to coordinated and integrated patient care. BMCH therapists expressed a desire to communicate with GPs and GPs expressed a willingness to increase communication with BMCH. At present there is no formal communication between BMCH therapists and GPs. Increased use of Team Care Arrangements currently funded under the Chronic Disease Management Medicare items could be one way to improve communication. Team Care Arrangements involve obtaining permission from the patient to contact all providers involved in their health care, and providers are required to provide feedback on the patient's progress.

Improved communication was the suggestion most frequently made by NCCC staff surveyed as a means to develop an improved working partnership between NCCC and BMCH. Collaborating with other services on suitable referral pathways to support the continuum of care should be priority for BMCH.

4. *Develop strategies to promote BMCH to clients and carers by increasing brand awareness in the local community, including ways to engage more male clients and carers*

Many people confuse BMCH with the Cancer Council, a much larger state-based non-government organisation. BMCH needs to build understanding about the organisation's focus on service delivery to the local community and the role community-based cancer support services, including complementary therapies, can play in helping women and men living with all types of cancer.

Currently, male membership in BMCH is low. Suggestions for attracting increased male involvement made at the stakeholder workshop included altering the brand image to make it more appealing to men, establishment of group activities which may be appealing to men or even the engagement of an ambassador from a sporting code. Further research is needed here.

5. *Promote consumer-driven health research and consumer involvement in all primary health care research and evaluation.*

The benefits of active consumer participation in health research and service development are increasingly being recognised. As demonstrated in this consumer-led research project, the knowledge that consumers bring based on their lived experience is invaluable in all stages of project planning, development and implementation. A collaborative, capacity-building approach, with all the researchers learning from each other, works well.

References

1. *Cancer in Australia: an overview 2012*. <http://www.aihw.gov.au/publication-detail/?id=60129542359> (Accessed July 2014)
2. Australia Institute of Health and Welfare (2012). *Cancer incidence projections: Australia, 2011 to 2020*. Cancer Series no. 66 Cat. No. CAN 62. Canberra: AIHW.
3. Australian Institute of Health and Welfare (2012). *Cancer survival and prevalence in Australia: period estimates from 1982 to 2010*. Cancer Series no. 69. Cat no. CAN 65. Canberra: AIHW.
4. The Gawler Foundation website. <http://www.gawler.org/> (Accessed July 2014)
5. Bloomhill Cancer Help website. <http://www.bloomhill.com.au/> (Accessed July 2014)
6. Quest for Life Foundation website. <http://www.questforlife.com.au/> (Accessed July 2014)
7. SolarisCare Cancer Support Centre website. <http://solariscare.org.au/> (Accessed July 2014)
8. Olivia Newton-John Cancer & Wellness Centre website. <http://oliviaapphttp://www.questforlife.com.au/eal.com/> (Accessed July 2014)
9. Chris O'Brien Lifehouse website. <http://www.mylifehouse.org.au/> (Accessed July 2014)
10. Seely DM, Weeks LC & Young S (2012). A systematic review of integrative oncology programs. *Current Oncology*, 19(6), 336–361.
11. Senate Community Affairs Reference Committee (2005). *The Cancer Journey: Informing Choice*. Viewed 15 May 2013, available at http://www.aph.gov.au/Parliamentary_Business/Committees/Senate_Committees?url=clac_ctte/completed_inquiries/2004-07/cancer/report/index.htm
12. Gillespie J, Leeder S, Paul T, Russell H & Usherwood T (2012). *A Report on the Health Needs of the Nepean-Blue Mountains Medicare Local Area*. Sydney: JustHealth Consulting & Menzies Centre for Health Policy.
13. *Blue Mountains Cancer Help Annual Report 2013*.
14. National Health and Medical Research Council (2014). *Talking with your patients about Complementary Medicine: A Resource for Clinicians*.

Glossary

ACUPUNCTURE: A traditional form of Chinese medicine in which fine, sterile needles are inserted into points along the energy channels in the body to re-balance energy and reduce symptoms related to cancer treatments.

ART THERAPY: A form of psychotherapy, in which participants create pieces of visual art to help them express their feelings in a non-verbal way, and which helps reduce tiredness, anxiety, pain and depression. Artistic talent is not necessary for people to benefit.

BOWEN THERAPY: A very gentle and relaxing therapy that consists of gentle rolling moves on the skin over muscle, tendons and ligaments in the body.

COUNSELLING: Allows exploration of problems and emotions in a safe, objective environment, helping to improve self-esteem, communication, relationships and decision making. A counsellor can simply provide a non-judgemental 'listening ear' to allow the client to talk through events that are causing confusion, grief, anxiety, guilt or conflicting emotions.

GROUP THERAPIES: 'General Support', 'Meeting the Challenge' and 'Art Therapy' groups are conducted regularly, providing emotional and psychological support for clients and carers in a group setting.

'LIVING WELL WITH CANCER' PROGRAM: Consists of 12 weekly sessions, conducted twice annually, to meet and help overcome the challenges of cancer. Sessions cover mindfulness and meditation practice, anti-cancer nutrition, understanding the body's capacity to heal itself, healthy emotions, pain management, and the connection between mind and body in relation to health.

LYMPHOEDEMA MANAGEMENT: Lymphatic drainage is a type of gentle massage which is intended to encourage the natural drainage of the lymph from the tissues of the body, and may assist in either the management of/or reduction of the risk of lymphoedema. Lymphoedema commonly occurs following breast or prostate surgery where glands are also removed.

MASSAGE: Reduces pain, fatigue, anxiety, depression, and nausea. Gentle touch is essential when clients are undergoing cancer treatment or recovering from it. All BMCH massage therapists are oncology trained.

QIGONG: A mind-body approach that uses physical activity and meditation to harmonise the body, mind and spirit. Medical Qigong for health and healing consists primarily of physical movements and breathing exercises combined with meditation.

REFLEXOLOGY: A type of bodywork where the practitioner massages zones on the feet that relate to different parts of the body. By pressing on reflex points, energy meridians are unblocked, relieving many symptoms, including nausea and fatigue.

YOGA: Classical Hatha Yoga combines gentle movements with the breath to relax and calm mind, body and spirit.



An initiative of Blue Mountains Cancer Help, the University of Western Sydney and Nepean-Blue Mountains Medicare Local.