Mind the gap

Shining a light on the vital role the third sector plays in supporting cancer patients

Job bag: ONC-GB-2300472
Date of Prep: October 2023

All.Can
Changing cancer care together

About **All.Can** UK

All.Can International is a not-for-profit organisation (ASBL) registered in Belgium. Its work is made possible with financial support from Bristol Myers Squibb (main sponsor), Roche (major sponsor), MSD and Johnson & Johnson (sponsors) and Illumina (contributor). Additional financial support for projects has been provided by Amgen. All.Can is a registered trademark of All.Can International.

If you would like more information on All.Can UK, please visit our website at: https://www.all-can.org/national-initiatives/uk/ or email the secretariat All.Can@hanovercomms.com.

This report was developed in 2023 by All.Can UK, with funding provided by Bristol Myers Squibb.

Contents

Introduction and Executive Summary 4
The psychosocial burden of a cancer diagnosis: an unmet need 6
What psychosocial support services are currently on offer for cancer patients and how can these be accessed 7
Plugging the gap: The value of third sector services 9
Case study: Fight Bladder Cancer 11
Case study: Shine 12
Conclusion 13
Recommendations 13
Appendix 14
References 15

Introduction and Executive Summary

A cancer diagnosis and subsequent treatment can be devastating and debilitating for the wellbeing of the person involved. In England, there are at least 130,000 people living with 'treatable but not curable cancer'[1] who are more likely to experience worry, fear or anxiety due to their condition.[2]

130,000 people in England living with 'treatable but not curable cancer' are more likely to experience worry, fear or anxiety.[1]

Evidence shows that the effectiveness with which cancer patients' mental health needs are met often varies significantly between organisations and regions. A key reason for this is that commissioning of support services aimed at addressing the psychological, social, financial and practical problems that people with cancer face comes from the different budgets, payment systems and contracting arrangements.

> This often results in a lack of any consistent approach to commissioning.[3]

Rethinking how services are commissioned would help improve patients' cancer care experience by enabling the system to begin to take a more holistic 'whole person, whole system, whole pathway' approach.[2] All.Can UK believe that there is a need to both rethink the way in which NHS cancer services are commissioned, and to further strengthen knowledge of and connections with third sector provision.

Voluntary organisations already provide many services aimed at addressing the psychological, social, financial and practical problems facing cancer patients and their families. The third sector plays a vital role in delivering these support services to cancer patients yet, to date, there has been no systematic assessment of their economic value both to the healthcare system and wider society in terms of costs saved. All.Can UK has tried to address some of this uncertainty in this report.

To do so, All.Can UK commissioned the Office of Health Economics (OHE) to conduct a literature review and develop a value proposition which estimates the 'service value' of psychosocial support interventions, including the efficiency savings they can deliver for the system.

All.Can UK has also drawn on insights from patient groups to gather data and qualitative case studies on the services that they provide to patients, as well as patients' experience of accessing and benefiting from these services.

The services offered by the NHS and third sector sometimes differ in terms of the nature of the intervention and setting, and should be considered complementary:

The services delivered by the NHS are more clinical in nature and include psychotherapy such as cognitive behavioural therapy (CBT) and antidepressants.

The services delivered by patient organisations and charities include helplines, online forums, beauty workshops and information booklets.

KEY FINDINGS FROM THE OHE'S ANALYSIS INCLUDE:

1. On average, each psychosocial intervention could save the NHS as much as **£1,083** per patient in the first year after the intervention. Cost savings are driven largely by fewer hospitalisations and inpatient days.
2. Total societal savings exceed **£300** per patient in the first year after treatment.
3. Mindfulness-based interventions deliver the largest cost savings and the greatest improvements in patient health.
4. At least **£53.2m** is spent each year by third sector organisations on psychosocial support services for cancer patients.
5. Based on an indicative modelling exercise, the third sector may be providing benefits worth **£77.7m** (£40.7m in cost savings for the NHS, and £37.1m in health benefits for patients). Therefore, the third sector may be delivering net monetary benefits of at least **£24.5m** per year.

Our findings show that psychosocial support services for cancer patients deliver important value to health systems and wider society even in the first year after the intervention. While it is difficult to estimate the full contribution of the UK's third sector in this space, it is clearly a significant provider of psychosocial support services in the UK, offering a range of services which are complementary to the clinical interventions provided by the NHS.

The psychosocial burden of a cancer diagnosis: an unmet need

Since the early 1990s, incidence rates for all cancers combined have increased by more than a tenth (12%) in the UK. This trajectory is expected to continue, with rates projected to further rise by 2% in the 15 years between 2023-2025 and 2038-2040.[4] However, due to advances in early detection and treatment, people with a cancer diagnosis are living for longer.

Cancer survival in the UK has doubled in the last 40 years and, in England and Wales, 50% of people with a cancer diagnosis will survive for 10 or more years (2010-11).[5] The increase in survival rates means that the number of people with cancer needing medical treatment and long-term surveillance is increasing.

The psychosocial burden of cancer is significant, with cancer patients needing support beyond their acute medical needs. An All.Can survey found that around 4 in 5 people living with cancer have stated that they needed psychosocial support during or after their cancer care.[6] The most commonly reported needs for psychosocial care include help coping with anxiety, depression, and fear of recurrence or progression, help with better communication of what to expect from treatment, and support for relatives, families, or spouses.[7]

Setting aside health system costs, the total lifetime psychosocial cost of cancer to individual patients could be in the region of £300,000 per patient.[8] These "quality of life" costs have been estimated to account for 2/3 of the total economic burden of cancer.[9] It is imperative cancer patients have their psychosocial support needs met in order to increase wider societal benefits from improving mental health such as patients being able to return to work.

> Even 10 years after treatment, 54% of cancer survivors still suffer from at least one psychological issue.[10]

> However, according to an All.Can cancer patient survey, of those who said they needed some form of psychosocial support during and after their cancer care, 50% (of 360 UK respondents) said it was not available.[6]

> Moreover, it was found that between 2008 and 2011, 73% (1130) of cancer patients with depression did not receive potentially effective care for their depression.[11]

What psychosocial support services are currently on offer for cancer patients and how can these be accessed

Psychosocial support for cancer patients aims to ameliorate the emotional, cognitive, social, and functional problems that can arise from patients coping with diagnosis and treatment.

These services may be provided at any point in the cancer care pathway, from diagnosis, to post treatment and end of life care. Services may be provided by formal healthcare providers such as the NHS, or voluntary third sector organisations such as patient organisations and charities. The NHS often works in partnership with third sector organisations to provide psychosocial support.

The commissioning of psychosocial support services for cancer patients in the UK is varied. The most common forms of funding for services include:

- Direct commissioning
- Block funding
- Macmillan grant funding
- Funding by tariffs

There are significant barriers in the way of ensuring routine access to services that support the psychosocial wellbeing of people living with and beyond cancer.

In 2022, All.Can UK held a roundtable with the *Health Service Journal* to explore these barriers in more detail and discuss potential solutions. The roundtable panel included individuals from the Royal College of Psychiatrists and North Central London Cancer Alliance. A key barrier cited was the 'conceptual separation' that exists between physical and mental health.[12] Different budgets, payment systems and contracting arrangements for cancer and psychological support services mean that there is often a lack of any consistent approach to commissioning of support services. This in turn leads to regional variation in the support on offer, with some geographical areas having no or limited access to psycho-oncology provision.[2]

A key barrier cited in All.Can UK's 2022 roundtable was the 'conceptual separation' that exists between physical and mental health.

Kelly, a cancer patient living in Bedfordshire, experienced these challenges first-hand. She says:

> *"I was given my Stage 4 diagnosis by a clinical nurse specialist (CNS) with no consultant present. When I asked for psychological support at this meeting, she said I wasn't entitled to it as I lived in a different county to the hospital. I said it was critical that I received help and she said she would look into it. Two weeks later, I finally saw a consultant. When I said I still didn't have any psychological support, he said they had a woman who "sits over there" (pointing to the end of the corridor), but that I couldn't speak with her as I live in Bedfordshire and the hospital is in Hertfordshire.*
>
> *I got very upset and said it was critical I speak with someone to help me process my devastating diagnosis. I eventually got support after five weeks of calling my GP directly and talking with my district nurse. It was offered via a charity though, not the NHS.*
>
> *I later changed hospitals and one of the first questions my new consultant asked was what psychological support I needed. It seems crazy that the NHS would spend thousands of pounds on my physical treatment in one place but that I couldn't get psychological help at the same time when processing a diagnosis of incurable cancer".*[13]

Plugging the gap:
The value of third sector services

Cancer charities, patient groups and other third parties provide crucial services which support the psychosocial wellbeing of cancer patients in many different ways, providing additional capacity in terms of care and support and complementing what is already available from the NHS.

These services can include emotional, social, physical and practical support. They might take the form of mentoring and coaching, support groups offering practical tips or led by therapists and clinical nurses, or workshops on skincare and wig advice. The grouped service types are summarised below. Providing this support to cancer patients represents an investment, which may be needed now more than ever given the disruption to services caused by the COVID-19 pandemic.

Service category	**Related third sector services**
Psychotherapy	• Psychological services involving trained healthcare professionals such as those provided by Maggie's and Macmillan • Support groups
Self-management Mindfulness	• Information booklets • Services to boost confidence
Mixed	• Multicomponent interventions delivered by healthcare professionals
Peer support including support groups	• Support groups • Buddy system • Forums

All.Can UK's analysis has found that, on average, each psychosocial intervention could save the NHS as much as **£1,083** per user in the first year after intervention.

All.Can UK have worked with the OHE to estimate the value of psychosocial support services provided by the third sector. A pragmatic literature review and indicative modelling exercise were undertaken to estimate the value of benefits of various types of psychosocial interventions. The subsequent analysis has found that, on average, each psychosocial intervention could save the NHS as much as **£1,083** per user in the first year after intervention.

Other key findings from the analysis included:

- Cost savings are largely driven by fewer hospitalisations and inpatient days.
- Mindfulness-based interventions deliver the largest cost savings (and the greatest improvements in patient health).
- From the evidence available, the interventions used in breast cancer delivered the largest cost savings (but non-site-specific interventions offered biggest health benefits).
- Total societal savings were estimated to be **£307** per patient in the first year after treatment.

An informal poll of a small group of charities (Shine Cancer Support, Action Kidney Cancer, Brainstrust and Look Good Feel Better) found that the majority estimated that their activities reach approximately 10% of newly diagnosed people with cancer in the UK. If it is assumed that the 10% reach of cancer charities is reflected across all people with cancer, it can therefore be estimated that approximately **37,540** newly diagnosed cancer patients access some form of third sector support service each year.

If the third sector saves the NHS £1,083 in costs per patient in the first year after intervention, then it can further be estimated that the third sector could save the NHS approximately **£40.66m** each year by providing key support services for newly diagnosed cancer patients. This does not include the **£37.1m** worth of health benefits also delivered.

Third sector spending on psychosocial support:

- At least **£53.2m** is spent each year by third sector organisations on psychosocial support services for cancer patients in the UK.
- Based on an indicative modelling exercise, the third sector may be providing benefits worth **£77.7m** (£40.7m in cost savings for the NHS, and £37.1m in health benefits for patients). Therefore, the third sector may be delivering net monetary benefits of at least **£24.5m** per year.

£24.5m
per year net monetary benefits

Case study: Fight Bladder Cancer

Population

Each year, **21,185** people are diagnosed with bladder cancer in the United Kingdom. In England there are **5,042** diagnoses of high-risk non muscle invasive bladder cancer and **3,269** diagnoses of muscle invasive bladder cancer each year.

Services

- 11 targeted patient booklets including patient testimonies
  - The booklets are available from healthcare professionals in hospitals and clinics across the UK. Patients and family members can also order them directly on the charity website.
- Tips and tricks from the Fight Bladder Cancer support forum.

Expenditure

In the financial year 2021/22, Fight Bladder Cancer spent **£73,984** on support activities (out of a total charity expenditure of **£326,648**).

Impact

Measured by recording the number of patient information booklets distributed to patients and carers, along with the preference for digital or print copies. A survey is also distributed to assess their needs, asking for the recipients' opinions on the value of the information and if they would recommend these resources to other cancer patients and carers.

fight bladder CANCER

Case study: Shine

Population

Shine Cancer Support provides care to young adults living with cancer. **37,000** young adults aged 25 to 49 are diagnosed with cancer each year. In 2021, **75%** of people Shine supported had either finished treatment (49%) or were in treatment (**26%**).

Services

Shine coordinates a variety of online and in-person support activities. These include in person social meet ups, 24/7 support via social media, small group discussions, talks and workshops and support for partners and carers.

Reach

As a small charity Shine Cancer Support reaches around **10%** of newly diagnosed patients aged 25-49 (around **4,000** people). People often struggle to access help or take quite a long time to realise that they may need it, so use figures may underestimate true need.

Expenditure

In 2021/22 Shine's charitable expenditure was **£191,000**. This amounts to approximately **£50** per user. There is variation in the costs of services. In-person retreats cost **£1,000** per person but economies of scale would lower these with higher uptake.

Impact

Shine run an annual impact survey. In 2021, **86%** reported that they feel better supported as a young adult with cancer since joining Shine. **86%** feel less anxious and **73%** feel less stressed. **83%** feel less emotionally isolated since connecting with Shine.

shine
CANCER SUPPORT

Conclusion

The modelling exercise and subsequent analysis outlined in this report demonstrates the value that psychosocial support services deliver to health systems and wider society both in terms of patient benefit and cost savings for the NHS. It is also clear that the third sector delivers a sizable contribution in the provision of psychosocial support for people with cancer, offering a range of services which are complementary to the clinical interventions provided by the NHS. If this support from the third sector did not exist, costs would likely have to be borne by the NHS during a time when the NHS is already facing financial constraints.

This report has highlighted how taking a holistic approach to a person's cancer care translates into improved patient experience and savings for the healthcare system through prevention of clinical escalation. However, more work is needed to unlock the potential to improve outcomes and experiences for patients and create further efficiencies for a healthcare system under immense pressure.

RECOMMENDATIONS

1. All hospitals responsible for diagnosing and treating cancer should have access to a psycho-oncology team. These teams will be able to provide expertise in psychological and mental health.
2. Integrated Care Systems (ICSs) should each include measures within their own plans to ensure that healthcare professionals working across physical, mental health and social care services are collaborating to improve patient outcomes.
3. Best practice must be shared between psycho-oncology teams in the form of training and consultation.
4. The regional variation in patient access to psychosocial services must be addressed through changes to how cancer care services are commissioned.
5. People with cancer must be involved in the decision making around their psychological well-being.

Appendix

Methodology

A pragmatic literature review and indicative modelling exercise were undertaken to estimate the value of benefits of various types of psychosocial interventions.

What is meant by "value"?

- When new treatments or services are being considered for routine commissioning in the NHS, they are generally evaluated according to their impact (compared with current practice) on:
  - Health outcomes: impact on a patient's health, captured using a generic measure of disease burden and summarised in a metric that includes the impact on both the quality and the quantity of life lived: the quality adjusted life year (QALY).
  - **Health care costs**: costs of delivering health care, including drugs, equipment, tests, GP visits, hospital days, downstream treatment costs, etc.
- Impact on cost (Cost change) is combined with impact on health (the QALYs change) to arrive at an incremental cost effectiveness ratio (Cost change/the QALYs change), which summarises the intervention's value, and represents the spending required to achieve one unit of health benefit.
- Evaluating services in this way helps the NHS use its limited budget to maximise health outcomes for the whole population, by prioritising the interventions with the best value.
- While the psychosocial services under consideration are currently funded by the third sector, in order to understand and communicate the value of these services and to support their continued investment, we estimate their potential value to patients and the healthcare system in those same health economic terms.

Limitations

1. It is assumed that services provided by the third sector are of the same effectiveness and have similar impacts on health service use as those that have been the subject of clinical trials.
   - Several of the interventions included in the modelling have been delivered in clinical settings by trained health care professionals. Therefore, the potential savings estimated in this analysis are contingent upon the assumption that psychosocial services delivered by the third sector offer similar benefits: this assumption should be tested and the basis of further research.
2. Cost savings and health benefits relate to the first year after the intervention only.
   - This is because most follow up periods are less than 12 months and extrapolating beyond this would be unreliable. It may take longer than 12 months for healthcare cost savings to be fully realised, so the total cost savings could be higher than our estimates.
3. The estimates are based on a small number of studies reporting uncertain impacts on costs and patient health.
   - Generally, there is a paucity of large sample randomised controlled trials (RCTs) which are needed to provide precise estimates of health and cost impacts, but which are difficult to generate in these settings and for these sorts of interventions.
4. Only studies that report quality adjusted life years (QALYs) or global health related quality of life using a widely used patient reported outcome measure (PROM) such as the EQ 5D have been included in the model.
   - These criteria were used because QALYs can be monetised relatively easily, but this significantly narrows down the evidence base.

REFERENCES

1. Macmillan (2021). Treatable but not curable cancer. Available at: https://www.macmillan.org.uk/treatable-but-not-curable-cancer#:~:text=At%20least%20130%2C000%20people%20in,cancer%20and%20extend%20people%27s%20lives [Accessed October 2023]
2. Transforming Cancer Services Team (2020). Commissioning guidance for cancer psychosocial support. Available at: Refreshed-February-2020-Guidance-doc-Psychological-support-for-people-affected-by-cancer-.pdf (transformationpartnersinhealthandcare.nhs.uk) [Accessed October 2023]
3. Transforming Cancer Services Team (2018). The psychological impact of cancer: commissioning recommendations, pathway and service specifications on psychosocial support for adults affected by cancer. Available at: Psychological-support-for-people-affected-by-cancer-May-2018.pdf (transformationpartnersinhealthandcare.nhs.uk) [Accessed October 2023]
4. Cancer Research UK. Cancer incidence for all cancers combined. Available at: https://www.cancerresearchuk.org/health-professional/cancer-statistics/incidence#heading-Zero [Accessed October 2023]
5. Cancer Research UK. Cancer Survival Statistics. Available at: https://www.cancerresearchuk.org/health-professional/cancer-statistics/survival#:~:text=Cancer%20survival%20is%20improving%20and,in%20England%2C%20Wales%20and%20Scotland [Accessed October 2023]
6. All.Can UK (2020). Placing the psychosocial wellbeing of people with cancer on equal footing to physical health. (on file)
7. Weis J. (2015). Psychosocial Care for Cancer Patients. Breast Care 10(2):84-86. Available at: https://karger.com/brc/article/10/2/84/53284/Psychosocial-Care-for-Cancer-Patients
8. Transformation Partners in Health and Care. Psychosocial support and cancer. Available at: https://www.transformationpartnersinhealthandcare.nhs.uk/our-work/cancer/personalised-cancer-care/psychosocial-support-and-cancer/#:~:text=Even%2010%20years%20after%20treatment,do%20not%20receive%20any%20support [Accessed October 2023]
9. Walker, J., et al. (2014). Prevalence, associations, and adequacy of treatment of major depression in patients with cancer: a cross-sectional analysis of routinely collected clinical data. The Lancet Psychiatry 1(5): 343-350. Available at: https://www.thelancet.com/pdfs/journals/lanpsy/PIIS2215-0366(14)70313-X.pdf
10. This statement is supported in the "ohe.org_Psychosocial support services for cancer patients in the UK: a value proposition_2022 (v1.0)". (on file)
11. Walker, J., et al. (2014). Prevalence, associations, and adequacy of treatment of major depression in patients with cancer: a cross-sectional analysis of routinely collected clinical data. The Lancet Psychiatry 1(5): 343-350. Available at: https://www.thelancet.com/pdfs/journals/lanpsy/PIIS2215-0366(14)70313-X.pdf
12. Essue, B.M., et al. (2020). The psychosocial cost burden of cancer: A systematic literature review. Psycho- oncology 29(11): 1746-1760. Available at: https://pubmed.ncbi.nlm.nih.gov/32783287/
13. All.Can UK (2022). We cannot meet the mental health needs of cancer patients without breaking down silos. HSJ. Available at: https://www.hsj.co.uk/policy-and-regulation/we-cannot-meet-the-mental-health-needs-of-cancer-patients-without-breaking-down-silos/7032316.article [Accessed October 2023]

All.Can
Changing cancer care together