

IMPROVING THE CANCER JOURNEY IN POWYS PROGRAMME



**ELECTRONIC
HOLISTIC
NEEDS
ASSESSMENT**



End of Stage Two Report - Summer 2022

Improving the Cancer Journey in Powys programme



Executive Summary

As a global pandemic gripped the UK in 2020, dramatic changes were enforced on the health and social care system. This significantly changed how cancer care was delivered and how people living with cancer were able to access the care and support they needed. The landscape for cancer has remained unchanged during this period with an increasing number of people receiving a cancer diagnosis, with 1 in 2 of us hearing the words “you have cancer”.¹ However, with continuing improvement in survival rates the landscape is positive, although there is a need to acknowledge that people living with cancer are not necessarily living well. What often makes the cancer journey more complex is the lack of coordination across the numerous people and organisations that people living with cancer come into contact with during their journey.²

Improving the Cancer Journey in Powys (ICJ in Powys) is an example of a new approach in developing a model for co-production and coordinating relationships between health and social care and local communities which delivers on the ambition set out in A Healthier Wales³ and the National Optimal Cancer Pathway⁴. The programme is a strategic partnership across Powys Teaching Health Board, Powys County Council and Macmillan and a range of community and voluntary organisations, people, and carers. This demonstrates the potential that a multi-agency, integrated approach to care and support as close to home as possible can deliver and this year ICJ achieved:

- **Commitment of delivery partners to the programme**
- **Increased cross organisational referrals**
- **Coproduced key documentation with forum members**
- **A new referral method to increase the offer of support close to home**

The key achievements of the past year evidence the impact that can be made and a workshop to ‘join the dots’ scheduled will ensure that we continue to work to ensure we build a comprehensive, high quality, personalised care, and support model for all. Joint Executive Sponsors and Senior Responsible Officers for the Powys ICJ Programme are: (left to right) Richard Pugh, Head of Partnerships – Wales & South West England, Dr Ruth Corbally Macmillan GP Cancer Lead, and the Clinical Lead for Cancer for Powys Teaching Health Board and Dylan Owen, Head of Commissioning, Powys County Council.



¹ Macmillan manifesto. 2022

² [Cancer care in Wales - CPES \(macmillan.org.uk\)](https://www.macmillan.org.uk/cancer-care-in-wales-cpes)

³ A Healthier Wales. Welsh Government. 2018

⁴ National Optimal Pathways for Cancer. Welsh Government. 2019

Background

Since initial discussions in 2016, Powys Teaching Health Board, Powys County Council and Macmillan Cancer Support have formed a strategic partnership to explore ways of improving experiences and ultimately outcomes for people living with cancer in the county. This centred on providing personalised holistic support for people living with cancer, to help meet their wider non-medical needs which an increasing evidence base shows, have an influence on an individual's cancer journey and their quality of life. This led to the development of the 'Improving Cancer Journey in Powys' programme (ICJ), inspired by the principles of the Macmillan ICJ programme that originated in Glasgow and is now mandated through Scottish Government under a £9 million roll out.

National and local policy aims to provide equitable access to holistic, seamlessly co-ordinated care and support, with a focus on wellbeing as well as physical health. People living with cancer in Powys do not have consistent access to personalised support close to home. Whilst they may receive support for some of their non-medical needs at their treatment centre, it is unlikely over the whole range of services that might meet their needs (including for example housing, welfare benefits, social services, transport, and travel). Furthermore, the experience of receiving support varies between treatment centres and depending on the person with cancer's circumstances. From a human rights and policy perspective, this creates an unacceptable inequity for the people of Powys. On a practical level there is growing evidence that supporting people with their holistic needs and concerns helps them cope better during and beyond their cancer journey, which can contribute to reducing avoidable and unplanned admissions. Using the successful guiding principles from the Scottish model, ICJ Powys has been shaped taking into consideration the unique challenges and opportunities within the county.

'Looking towards the future of personalised care – irrespective of health condition – health and social care professionals, patients, and their families, should come together to identify what support is needed, make goals, and take action, while monitoring every aspect of the process. This is no longer an aspiration. ICJ has provided the framework to follow'⁵

This is the focus of Improving the Cancer Journey in Powys:

to develop a sustainable, supportive, integrated community model of care to support people living with cancer in Powys

The partners in Powys may not be able to influence the provision of specialist cancer treatment closer to local people's homes, but it is within their control to bring quality personalised support closer to people's homes. Together, they have the resources, skills, relationships, and remit to develop an integrated and streamlined support model that meets local people's needs and reflects the county's unique context.

⁵ Evaluation of Improving the Cancer Journey (Scotland). Edinburgh Napier University. 2020

Introduction

The programme strategy, management and vision for delivery is a multi-agency approach to care, aiming to improve the quality of life and outcomes of people living with cancer in Powys. ICJ Powys aims to ensure that every Powys resident⁶ with a cancer diagnosis is offered a personalised ‘what matters to me’ supportive conversation, which explores their holistic needs and the offer of a care plan with access to appropriate support as close to home as possible throughout their journey and times of need (as depicted in Figure 1 right), making every contact count⁷.



Figure 1 - Macmillan Times of Need infographic

This provides an opportunity for local communities to work together co-producing where appropriate with health, social care, education, housing, leisure, the third sector and wider partners developing plans of how to spread innovation and best practice. ICJ in Powys is an example of a new approach in developing a model for co-production and coordinating relationships between health and social care and local communities and delivers on the ambition set out in A Healthier Wales⁸ and the National Optimal Cancer Pathway⁹ going beyond treatment in providing comprehensive personalised care for all.

Once these delivery approaches have been externally evaluated, the intention is to develop a business case for extending provision of the successful approach(es) across all Powys residents living with cancer. This will give an opportunity to explore other long-term conditions using existing capacity and identifying additional resource required within the community, voluntary and statutory sectors, until the needs of Powys residents are understood fully.

Progressing through Year 2

Building on the foundations set in year one, progress through year two was key to continue the momentum that was building.

⁶ Aged over 18 years

⁷ National Optimal Pathways for Cancer. Welsh Government. 2019

⁸ A Healthier Wales. Welsh Government. 2018

⁹ National Optimal Pathways for Cancer. Welsh Government. 2019

Theory of Change

To maintain cadence and progress through year two it was agreed to undertake a Theory of Change¹⁰, facilitated by an external provider, to ensure all stakeholders were fully engaged and integrated with the programme and also to ensure that there was a clear understanding and shared vision of how to progress, a 'North star', thus, enabling key stakeholders at all levels to understand their contribution in improving health and social outcomes for Powys residents living with cancer, key challenges and assets were identified during the process:

Challenges for planning and delivering services



- Rural geography is combined with high levels of rural poverty



- Population density is low across much of the county; many people live far from a town, and the towns themselves are relatively small with limited services.



- Digital connectivity is very poor outside the main towns, which can prevent use of online tools and delivery models



- Digital poverty prevents many people from using online services even where connectivity permits

Assets that can support local service innovation



- A vibrant voluntary sector committed to supporting local people



- A strong partnership between the Health Board and County Council that pre-dates the recently introduced Powys Regional Partnership Board



- The NHS Wales Optimal Pathways have been developed which also describes where patients should receive consistent information and support, tailored to meet their needs as part of the Suspected Cancer Pathway programme of work



- A genuine commitment to improving the cancer journey for local people with strong relationships across the three strategic partner organisations and a small number of key partners in the voluntary sector



- Legacy of Macmillan Cancer Community Framework Programme: engagement with primary care teams to include GP practice cancer champions and community pharmacies to be integrated within team ICJ going forward



- Successful Protected Learning with both clinical and non-clinical primary care colleagues, with the presentation of the ICJ Powys programme – envisaged to be a bi-annual event



- A priority within Powys Health & Care Strategy is digital transformation, to increase connectivity and reduce digital poverty
- Recent Health Board appointments of Wales Cancer Network Suspected Cancer Pathway Project Manager and Cancer Pathway tracker enables tracking
- Existing partnership between the council and Macmillan's funded Welfare Benefits Services within existing Money and Advice service
- Coproduced letters, newsletter, Top Ten tips, and CNS leaflet from the forum with lived experience

¹⁰ Improving the Cancer Journey in Powys Theory of Change. Brightpurpose. 2021

The programme is outcomes focused and working to define priorities to develop the key performance indicators and desired outcomes of the work undertaken following a period of organic growth and key learning. Theory of Change supported the formulation of three theories to focus the programme at individual, system, and community level in order to work towards detailed key performance indicators. These theories are underpinned by the Health and Care Strategy 2019¹¹ and supports the delivery of the PTHB Integrated Medium Term Plan¹².

Theory 1 – improving people’s quality of life and ability to self-manage

Building on the ‘what matters to me’ supportive conversation, people can work with a trained link worker to coproduce a simple plan to support their needs. These needs may be physical, emotional, practical, social, or financial. Identifying and discussing concerns raised allows for the formulation of the care plan with information to support self-management and referrals to support organisations. Offering a supportive conversation to people living with cancer can help to address these needs around the time of diagnosis, throughout treatment and essentially, when the active treatment period is over. The validated Holistic Needs Assessment tool is a supportive intervention used to identify what issues a person living with cancer might be facing at different points in their cancer journey.



At least **1 in 4** of those living with cancer – around **625,000 people** in the UK – face poor health or disability after treatment.

Over 70% need emotional support – research shows that 2 in 5 people living with cancer are affected by depression, and 1 in 10 experience anxiety.

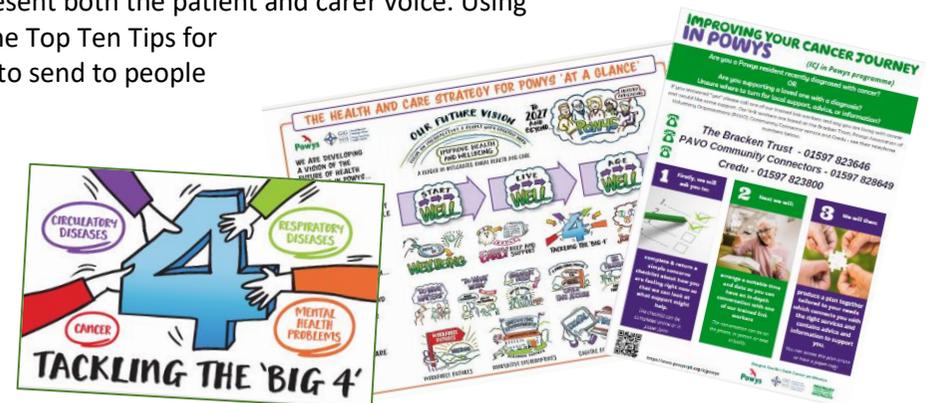
4 in 5 people living with cancer experience a financial impact. The average is £734 a month



THE IMPROVING THE CANCER JOURNEY IN POWYS JOURNEYING TOGETHER FORUM

One of the successes of this year has been the co-production of a number of key documents with the Journeying Together Forum, our forum of members with lived experience, who represent both the patient and carer voice. Using their experience and journeys they have co-produced the Top Ten Tips for people on their cancer journey, written a letter for GPs to send to people newly diagnosed, named, and edited our newsletter Caring About Cancer in Powys. They also coproduced a leaflet that Clinical Nurse Specialists will be sharing with all Powys patients who attend acute sites for their treatment. These key documents will promote the support that is available and enable people living with cancer to access that support.

Figure 2 - Infographic on the impact of cancer¹³



¹¹ Powys Health and Care Strategy 2019

¹² Powys Teaching Health Board Integrated Medium Term Plan, 2019

¹³ Macmillan Social Prescribing for Cancer Patients: a guide for primary care networks. Macmillan. 2020

Theory 2 – creating a county-wide network of cancer-confident organisations

Understanding what support and services are available locally and using the assets available in the county is vital. Engagement of key delivery partners creating the foundation for the network of organisations to develop. A community model of care is being naturally developed within existing partner organisation resources as delivery partners.

- The Bracken Trust are a nurse led organisation empowering people to live with, through and beyond cancer. Nurses offer the eHNA as part of the introduction to the trust. Offering a range of inhouse support and services the Trust in partnership with Macmillan have an existing information and support service which in 2020 received their second Macmillan Quality Environment Award.
- Powys Association of Voluntary Organisations (PAVO) community connectors deliver a non-medical model of support. With over 4000 member organisations who offer a broad range of support. PAVO initially trained three of their community connectors to offer the eHNA and went on to train a further three connectors due to the positive experience of both those completing the eHNA and the connectors offering the supported conversation.
- CREDU works to support carers across Powys. A personalised supportive conversation forms part of the introduction. Completing the eHNA may not always be the right approach for carers but having the supportive conversation is at the core of the ICJ in Powys programme.
- Powys Teaching Health Board's Specialist Palliative Care Team are able to offer the eHNA to their patients where appropriate.



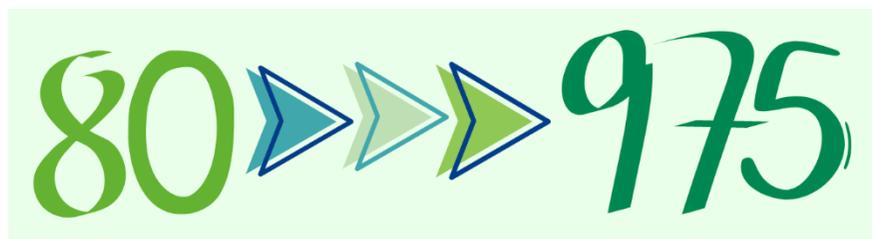
A key critical success for the programme has been the commitment and dedication of our delivery partners who have, in collaboration, worked to deliver the vision of the programme. With their expertise and knowledge of the assets and resources available in Powys a community support system is forming to ensure coordinated support across the county.

A further significant achievement this year is that Delivery Partners have increased cross organisational referrals and now attend PCC Adult Social Services Information and Support Team (ASSIST) meetings meaning:

- 
 - Quicker referrals
- 
 - Earlier access to support
- 
 - Increased number of supportive conversations
- 
 - Improved partnership working
- 
 - Increased knowledge of each other's services
- 
 - Peers support meetings to share learning and information
- 
 - Already reaching further than cancer

| | |
|------------------------------|------|
| Hopelessness | 6.9 |
| Other medical conditions | 6.64 |
| Tired, exhausted or fatigued | 6.64 |
| Uncertainty | 6.57 |
| Money or finance | 6.27 |
| Breathing difficulties | 6.13 |
| Moving around (walking) | 6.13 |
| Person who I look after | 6.11 |
| Eating, appetite or taste | 6.07 |
| Worry, fear or anxiety | 5.94 |

Figure 3 – Top 10 highest rated concerns raised April 2021-March 2022



In the last year 80 eHNAs were initiated which identified 975 concerns. Figure 3 above depicts the concerns with the highest average score. PLWC were supported in the most appropriate way, whether that was information and support or referrals to appropriate organisations. The new referral model for 22-23 will see this number rise significantly.

Theory 3 – building the evidence base for service development

The Theory of Change and the planned monitoring and evaluation framework will inform the ongoing collection of data for ICJ Powys and will be used as a programme design and continuous improvement tool which is ‘live’ and adaptable. It will help shape the planned evaluation of the service, which will seek to capture formative learning and evidence of effectiveness and impact.

The eHNA provides a consistent framework and recording system, so ICJ Powys can identify unmet needs and gaps in service. This can inform planning and development of more comprehensive services in Powys and influence wider conversations about strategic infrastructure development. Engaging meaningfully and continually with people living with cancer to shape our work alongside analysing the eHNA data will support development of services to address unmet needs (more information available on request).

Commissioning an evaluation to enable learning, improvement and demonstrating the difference being made.

The second Cancer Patient Experience Survey, carried out in partnership with the Welsh Government¹⁴, found that only 48% of people felt that they had been given adequate signposting and information about financial help and benefits. Only 49% felt their family was equipped with the right information on how to care for a loved one at home. Powys residents travel to England or across Wales given the absence of District General Hospital and rely on NHS Trusts and Boards outside the county. This means people always have to travel for specialist treatment, diagnostics, and aftercare¹⁵ and so ICJ Powys enables the opportunity to understand models for Powys offering care closer to home (see figure 4 for cancer commissioned services).

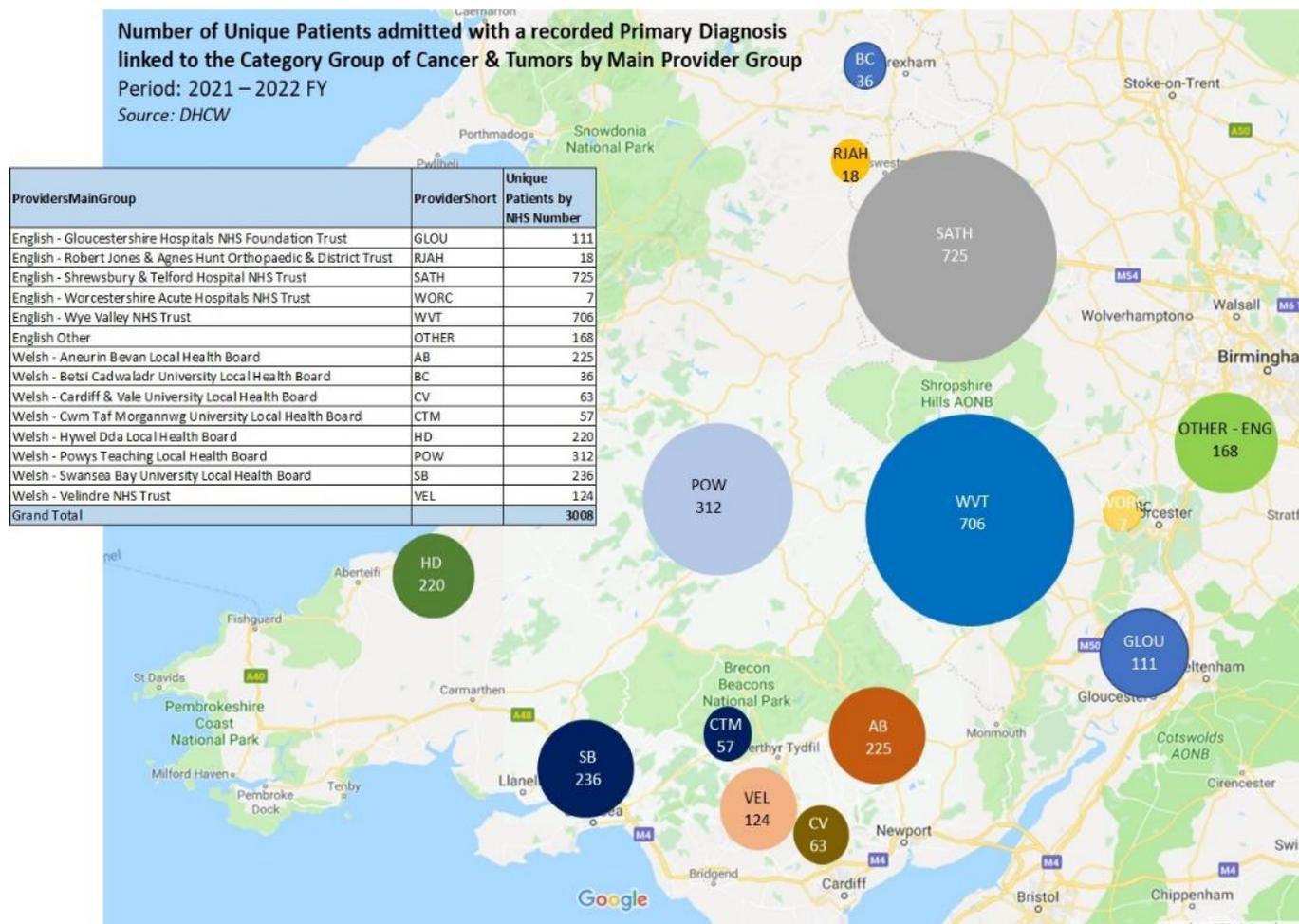


Figure 3 - Map of cancer patient admissions
 Map sourced from Google

¹⁴ [Cancer experience | Our research - Macmillan Cancer Support](#)

¹⁵ Improving the Cancer Journey in Powys Theory of Change. Brightpurpose. 2021

Engagement with the those involved throughout the cancer pathway has driven the whole system approach to change in Powys, with the alignment of the desire and drive to improve the cancer journey for people living in Powys.

Positive engagement and relationship building with the commissioned services (See figure 5) has formed the new community model of referring people back to ICJ in Powys to access the supportive conversation as close to home as possible as demonstrated in figure 5.

This forms the focus for the coming year and the target of 40% of new diagnoses' to be offered a supportive conversation, at a time that is right for them and as close to home as possible.

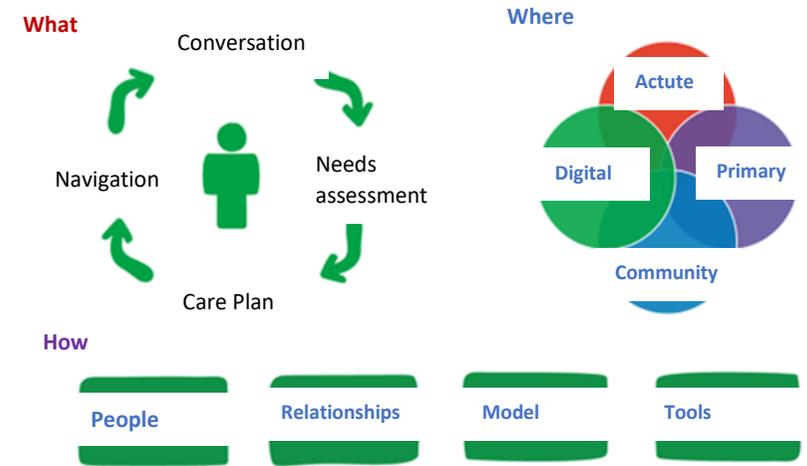
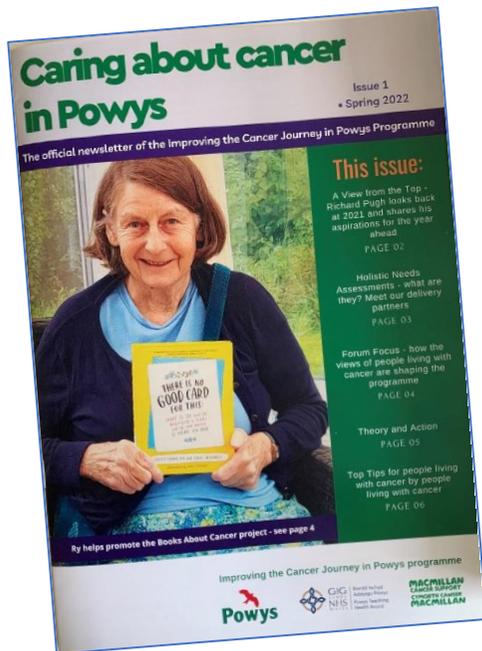
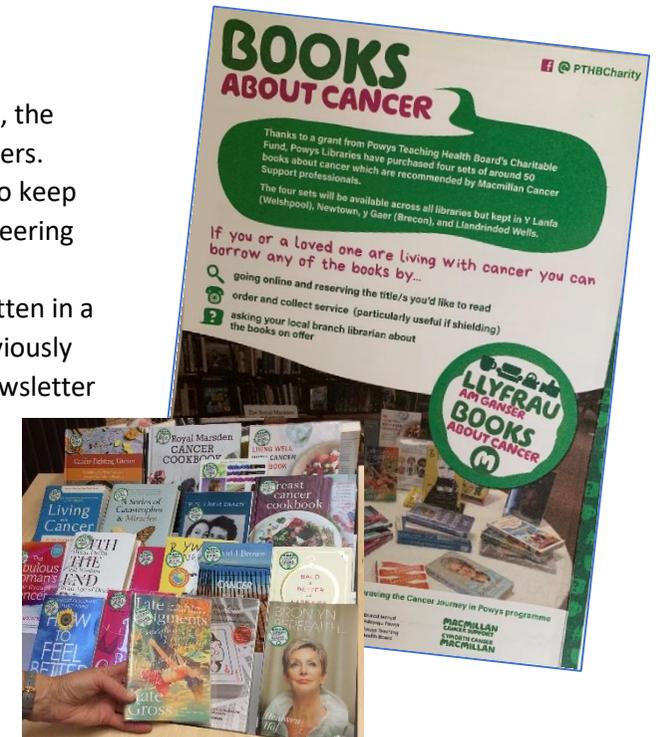


Figure 4 -Powys ICJ Community Model (adapted from Macmillan Strategy infographic)

Journeying Together Forum



A significant element of the programme is the Journeying Together Forum, the forum of people with lived experience, representing both patients and carers. Elected members attend the strategic, operational and evaluation board to keep the voice of people living with cancer embedded in the programme and steering the direction. As mentioned above, the forum co-produce some of the communication and engagement products in order to ensure they are written in a way that is appropriate for people living with cancer. As well as those previously mentioned the main focus has been on producing the first ICJ in Powys newsletter and promoting the books about cancer.



Looking to the future

Two years into the programme it is time to drive forward, the firm foundations have been built during this time and we have now reached the stage where we start “joining the dots” and build a comprehensive, high quality, personalised care, and support model for all. To take this forward a strategic visioning event is being held 3rd August 2022 to reset the programme and refine priorities by planning and building on the achievements and successes to date. These next steps will inform funding applications going forward.

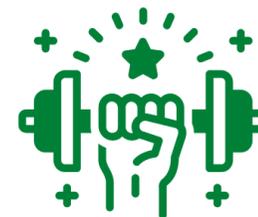
There are key areas of focus for stage 3:

1. Continue to strengthen the new (opt out) referral model to ensure that all people being diagnosed with cancer are referred into Powys to be offered personalised, tailored information and support as close to home as possible, achieving a target of 40% of new diagnosis’ being offered a supportive conversation closer to home. Promoting partnership working to ensure effective use of services and ensuring non-duplication to ensure there is less disruption to the individual by ensuring an inclusive, collaborative, and coordinated approach is embedded across our partners.

2. Build on the work undertaken under the Macmillan Primary Community Cancer Framework programme and secure primary care as a key stakeholder in the programme with the role of the Health Board Cancer Tracker and explore the opportunity of a Community Cancer Clinical Nurse Specialist and Cancer Navigator team to support the whole system change. This would ensure that people affected by cancer feel fully supported from the point of referral, and that their holistic needs are understood and addressed via clear, seamless, and accessible pathways of care, across organisational and professional boundaries

3. Use the assets of Powys which exist within the community to improve accessibility to information and wrap around support across the County.

What we know is that it can be confusing, disorientating and sometimes impossible to make sense or know how to access information and support, particularly outside of the healthcare support available at the many cross border hospitals that the residents of Powys attend for their acute care. We know that not all people living with cancer in Powys know how to access support or information¹⁶ and ICJ Powys needs to ensure that the opportunity of a supportive conversation is made available at a time which is right and as close to home as possible. ICJ Powys asset mapping involves identifying any services, support, or networks already available locally for people living with cancer, or that can be expanded to include cancer care. These services need not be cancer specific but simply responsive to the needs of people living with cancer.



¹⁶ Macmillan Cancer Patient Experience Survey 2016

Setting out how we deliver our strategy this year and beyond, and detailing what we will do to achieve our objectives and clarify our priority deliverables for 2022 and onwards follows on from the Theory of Change methodology which identified two areas of priority which were agreed taking the learning from ICJ Scotland:

- physical activity and exercise opportunities
- provision of quality holistic community information and support models¹⁷

3 a. Physical activity and exercise:

Appropriate advice and support regarding physical activity can be essential for people living with cancer from the time of being diagnosed, through treatment and recovery and to prevent effects of treatment and recurrence of cancer. It is important to understand where people living with cancer can be signposted or referred to locally and to understand the benefits that this could bring.¹⁷

3 b. Provision of high-quality information and support:

Currently there are more than 5000 people living with cancer in Powys, with the number likely to increase with approximately 1000 new diagnosis per year¹⁸. ICJ Powys is focused on ensuring that people living with cancer live life as fully as they can and the provision of high-quality information and support at non-clinical sites will support this. With an information centre at the Bracken Trust and the accessibility of libraries, there is an opportunity to support people living with cancer in the community, supported by PAVO Community Connectors, with hubs for information, support organisations and activities taking learning from ICJ Scotland.

Securing continuity to phase 2 will enable a whole system approach, building on previous programmes in primary care, utilising resources within the community and connecting to acute sites outside the county. Phase 2 will enable the development of work achieved in Phase 1 to establish the system change as business as usual and embed the processes to support people living with cancer in Powys.

For further information on anything included in this report including a different format please contact ICJPowys@powys.gov.uk

¹⁷ Macmillan Move More Programme 2019

¹⁸ Welsh Community Care Information System 2016