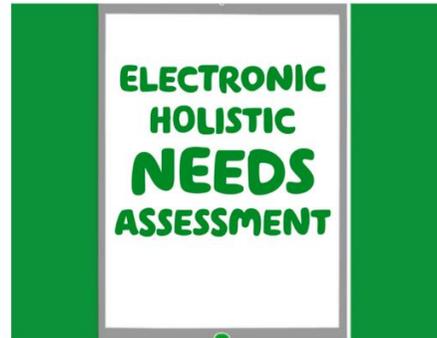


IMPROVING THE CANCER JOURNEY IN POWYS PROGRAMME



End of Stage One Report - April 2021

Improving the Cancer Journey in Powys programme



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FOREWORD

We are pleased to share with you our first End of Year report into the Improving the Cancer Journey in Powys programme – a three year collaboration – to ensure that everyone living with cancer in Powys gets the right help and support to achieve what matters most to them.

We cannot wind the clock back to before the pandemic. Instead, we will be embracing the best of the innovation and collaboration that the response to Covid-19 provoked. This is a timely moment to ‘reset’ cancer services and take this ICJ opportunity in Powys to review how the services which people with cancer need, not just in hospitals, but in all parts of the system including primary and community settings, work together to deliver personalised care for people with cancer: all vital parts of the ‘cancer and long term condition jigsaw’. Covid-19 risks having a long-lasting and traumatic impact on patients’ experience of cancer care with delays, disruptions, and immense challenge. We need to listen, learn, and do whatever it takes to address this within the scope of the Powys ICJ programme.

It is essential to appreciate that the Powys ICJ programme has successfully delivered some core elements of work planned in the most challenging of years whilst acknowledging that the pandemic has had an impact on aspects of many lives, none more than Health and Care sector staff who work jointly to provide services for the people of Powys. We would like to take this opportunity to record thanks to our teams for their professionalism, courage and commitment while caring for Powys residents.

Finally, we would like to say a special thank you to all the people who participated in this programme so far. Your knowledge and experience are helping shape the next steps to ensuring people living in Powys receive the high quality cancer care and support they need as the Programme is demonstrating that change can be coproduced and delivered with dedicated programme expertise and support.



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EXECUTIVE SUMMARY

This report summarises the work undertaken in Year 1 by the Improving the Cancer Journey in Powys Programme (Powys ICJ), a strategic partnership between Powys Teaching Health Board (PTHB), Powys County Council (PCC), and Macmillan Cancer Support (Macmillan). It identifies the programme's achievements and makes recommendations for how to take the work forward in order to continue to improve cancer patient journeys within Powys.

The overarching strategic ambition of the Powys ICJ is to make sure everyone living with cancer gets the support they need and are empowered to self-manage their identified needs, where appropriate, with support close to home in their local communities. This will be underpinned by every person living with cancer being able to have their needs assessed. This initial three year programme which commenced in January 2020 aims to do this through increasing understanding of the cancer patient experience and cancer pathways in Powys in conjunction with piloting a validated electronic holistic needs assessment tool in new health and care settings and other voluntary/third sector organisations.

We know cancer pathways are complex, cancer journeys are individual and often very complicated and clinical teams delivering treatment, care, and support for Powys residents, work very hard to try to join it all up. This commences from the time a person receives their cancer diagnosis, as they go through treatment and then for some onto recovery and for others onto living with cancer that is treatable but not curable, and when they transition to palliative care and enter the end of their life. These are the times when needs are severe, and by working jointly in strategic partnership the Health Board, Council and Macmillan have the capability and the potential to make the biggest difference by collectively putting people living with cancer at the heart of delivery.

The successful set up and implementation of the programme governance sets the foundation to support and enable delivery planning. The Strategic Programme Board has strategic oversight and governance responsibilities and meets bi monthly. The management and delivery of the Programme is through an operational group, chaired by the ICJ Programme Manager which meets monthly to review progress against action plans and escalate risks as appropriate to the Strategic Programme Board. In turn learning and progress for information is shared with the Powys Regional Partnership Board.

The Powys ICJ programme has brought together a small number of dedicated, committed, and enthusiastic organisations who are willing to share their time, thoughts, and experiences in order to improve services going forward in collaboration. As a result, the programme strategy, management, and vision for delivery is demonstrating a multi-agency approach to improving the provision of holistic care and support for people affected by cancer in Powys based on a structured individualised assessment and supporting care plan using the validated Macmillan electronic holistic needs assessment tool (eHNA).

In its first year, the Powys ICJ programme has successfully set up four pilot sites to use the eHNA tool within their organisations. These include the Bracken Trust, Credu, Powys Association of Voluntary Organisation (PAVO), and the Powys Health Board's Specialist Palliative Care team which will go live shortly. In addition, these organisational insights into existing systems and pathways are invaluable and ensure some understanding of the current baseline enabling

true coproduction of new improved service models. This collaboration also reflects the agile nature of the programme in responding flexibly to issues of significance to mitigate concerns and risks at the earliest opportunity wherever possible.

Another of the Programme's biggest achievements to date has been to engage with service users and the broader cancer community in Powys. The programme in Year 1 has set out to understand what works best and what needs to change to provide the best possible care and support to people affected by cancer in rural Powys and also their families and carers. A key strength of this programme has been from the beginning that people's knowledge, views, and experiences are being actively sought to co-design models. A Reference group has been established with representation to include service users and carers as co-production is at the heart of the programme reflecting the communications and engagement strategy and delivery plan.

The programme currently faces a number of challenges, in particular with the time limited nature of the Programme. These challenges relate to recruitment, inequitable tenure of contracting with risks associated with retention of the Programme team. Also, the initial Programme plan for Year 1 included commissioning a theory of change for the service and to design a monitoring and evaluation framework. Unfortunately, this external evaluation has not been possible as the Programme was interrupted by the outbreak of the COVID-19 pandemic in March 2020. So as a consequence, much of the feedback in this report is naturally qualitative as opposed to quantitative.

Macmillan, supported by the Health Board and Council Senior Responsible Officer's, made the joint decision to pause the Programme for 3 months with the Health Board programme team redeployed into the Commissioning and Planning directorate as the immediate focus at this time had to be supporting the operational delivery of health and care services during the pandemic. However, this has enabled a greater understanding of cancer pathways in Powys and the commissioning challenges as well acknowledging the informatics difficulties in tracking the cancer patient's progress within their pathway which is critical to the success of Powys ICJ.

Exciting work ahead for Year 2 includes developing, as a priority, the Theory of Change methodology through stakeholder engagement and workshops and also commissioning the external evaluation to support the monitoring and evaluation framework for the programme. Next steps also include engaging with NHS providers cross border in England and South Wales. This will test joining up key transitions points in the cancer patient's journey to develop a more streamlined and seamless approach to personalised assessment and care planning with the eHNA so that people living with cancer can access support that meets their needs in their own communities within Powys.

INTRODUCTION TO THE IMPROVING CANCER JOURNEY (ICJ) IN POWYS PROGRAMME

“You have got cancer” are words no one wishes to hear. However, some 1000 Powys residents will hear them each year. While cancer research is allowing the development of new treatments that are improving cancer outcomes to the point where some cancers are now becoming more like chronic disease with which people die rather than from which they will die. However, there is more to the cancer journey than just the medical treatment pathway. Evidence has been published in peer reviewed journals that medical issues are not the only factors that influence the individual patient’s cancer journey. Issues such as employment, housing, finances, and family welfare affect psychosocial welfare which impacts on resilience and the ability to tolerate cancer treatments.

The holistic approach to cancer care was the centre of the Macmillan Cancer Support work in Glasgow known as “Improving the Cancer Journey” or ICJ. The work there has been widely reported, quoted, and acknowledged for the outcomes that it achieved. Such has been its success that it is also being exported into the Highlands and Islands; a very different environment to the inner city that was the backdrop for the work in Glasgow.

Background to Powys ICJ Programme

Since 2016 the strategic partnership between Powys Teaching Health Board, Powys County Council and Macmillan Cancer Support has been evolving. A strategic partnership visioning event was hosted by Macmillan in November 2017. Growing momentum and interest in developing a person centred care delivery model for Powys enabled a second event in April 2019 with wider interested stakeholders. The keynote speaker was Carol Shillabeer in her capacity as CEO Powys Teaching Health Board/Joint Regional Partnership Chair. Sandra

McDermott, the then Head of Financial Inclusion and Improving the Cancer Journey Glasgow City Council, also returned to present and share Scotland’s transferable learning and relevance for Powys. A clear mandate followed to adopt the guiding principles of ICJ Scotland for Powys with the programme fully funded for three years by Macmillan. This includes two programme delivery posts, hosted by Powys Teaching Health Board and a communications and engagement officer, hosted by the Powys County Council.

The Powys Improving Cancer Journey initiation workshop was launched in January 2020 with the following aims developed and agreed within overarching strategic delivery plan:

Stage 1: Build on current knowledge and understanding of the needs of Powys residents affected by cancer.

- Develop a deeper understanding of issues and experiences for residents of Powys. Residents in this sense means people aged 18 and who are registered with a GP in Powys
- Hold ongoing conversations with those affected by cancer via various engagement events/multi-media resources
- Establish a cross section of health, council and third sector staff perception of issues and experiences for residents diagnosed with Cancer of Powys
- Desktop exercise to review and gather information around where residents diagnosed with cancer receive their treatment and around the ways in which holistic needs assessments are being carried out

- Based upon the information gathered, trial and evaluate a number of approaches
- Output: Report and recommendations to Strategic Programme Board

Stage 2: Develop, implement, test, and evaluate different options (models) for Powys.

- All individuals affected by cancer within the pilot testing to be offered a supportive conversation, based on their needs, out of which a care plan and relevant supporting arrangements will be developed.

Stage 3: Develop the preferred model into a business case.



Cancer is one of the big four diseases affecting peoples' lives in Powys

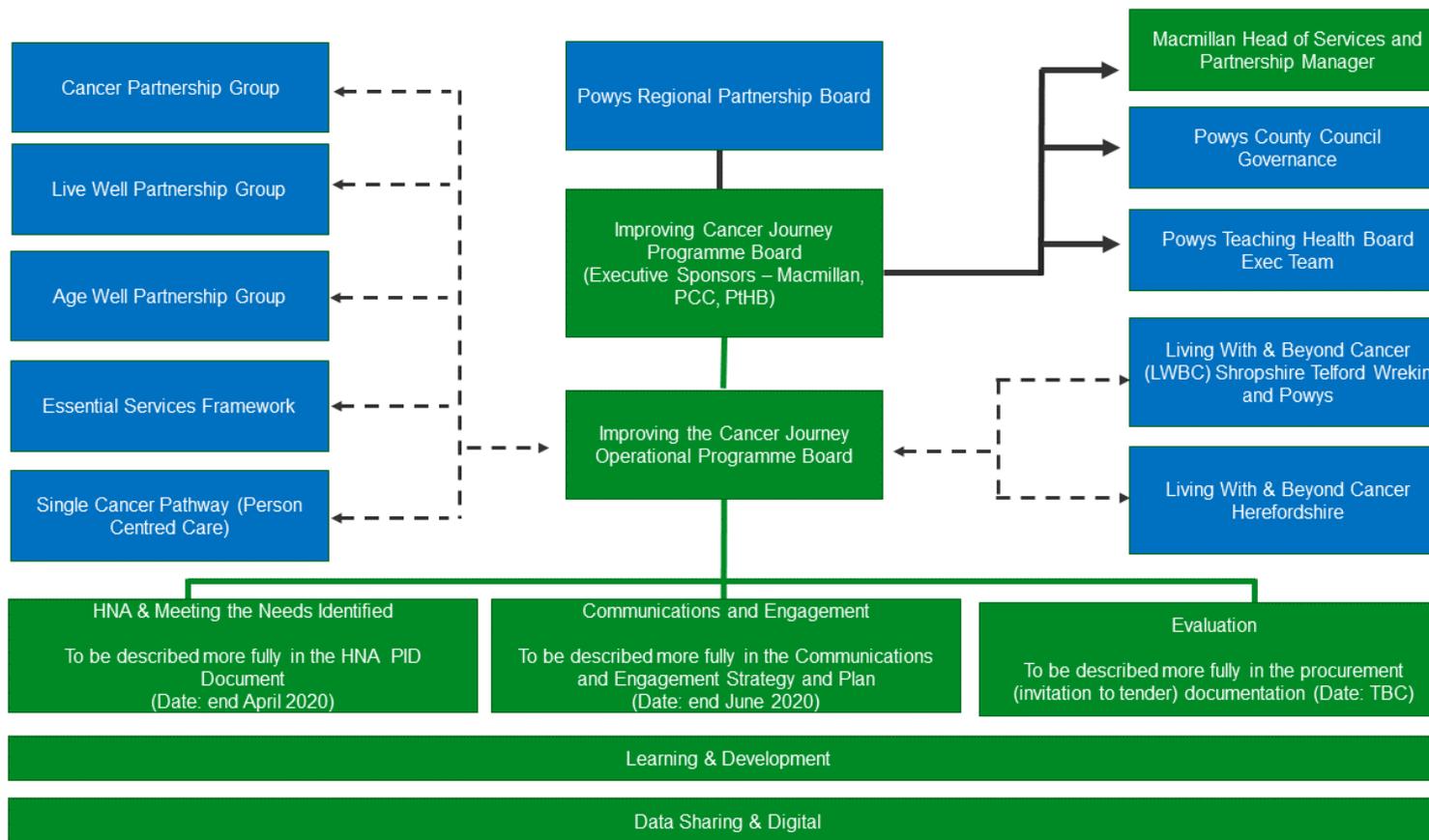
The first requirement of the programme was to put in place the Governance Architecture and this was achieved with the publication of the Programme Initiation Document and the agreed meeting architecture. At the start of the programme, diagnostic services were out of scope as was patient tracking and the decision as to which single transferable holistic needs assessment tool would be used had not been taken. Over the course of this first year, however, there has been considerable real time feedback on cancer services which has resulted in some re-drafting of the programme scope.

The main focus of activity during the first year of the programme was to have been outreach to patients on their cancer journey and a programme of engagement was developed. A particular emphasis was placed on trying to reach those that, frequently, are unable to engage in co-production opportunities and it was acknowledged that there might be a requirement to go "door to door" in order to engage those who were unable to engage either on-line or at in-person at engagement events.

In addition, a new theme emerged very quickly which has become a major work stream, it being the development and roll out of an equitable, transferable, patient owned electronic health needs assessment (eHNA).

GOVERNANCE AND EVALUATION

While the ICJ is a patient focussed programme, there is a requirement to put in place a robust governance process to demonstrate to strategic partners how charitable investment has been used and accounted for. Our Programme Initiation Document set out the agreed Governance Architecture in detail, with work streams overseen by an Operational Group which in turn reports into a Strategic Programme Board. They in turn share information and updates with the Regional Partnership Board. This is depicted in the organogram below. Initially, our intention was to meet quarterly as a Strategic Programme Board and to have monthly Operational Group meetings. The programme was paused during Covid and with the programme relaunch in July 2020, it was agreed that it would be easier to oversee and provide strategic direction and continuity for the ICJ programme with more regular and shorter bi-monthly Strategic Programme Boards.



Shortly thereafter, it was agreed to modify the reporting arrangements to bring them in line with the bi-monthly meetings and so the two different reporting templates were edited and merged. It was agreed to report progress on a bi-monthly basis to the Strategic Programme Board. These reports include detail on the progress and highlights of the previous period and describe the focus for the next period.

There is also a programme status breakdown by schedule, scope, cost and benefit and update against milestones. The report includes detail around Risks, Assumptions, Issues, and Dependencies. (RAID).

HEALTH CHECK

In November 2020, the programme team participated in an Annual Health Check with Macmillan which covered and rated a number of topics using a RAG system. The Red, Amber, Green depicted clearly what status the programme was at and reflected both the positive work achieved to date and also outlined areas for further work and action. The final report is summarised below.

Topic	RAG Status	Commentary
Vision and Strategy	GREEN	The programme vision and strategy is very closely aligned with those of the three strategic partners; Macmillan Cancer Support, Powys County Council and Powys Teaching Health Board.
Stakeholder Engagement	GREEN	There is a well-developed stakeholder strategy and plan looking at service providers and people living with cancer (PLWC) and their family's/carers. Consideration has been given as to how to engage the hard-to-reach communities.
Governance	GREEN	The Governance Architecture is in place covering the three strategic partners. What remains to be finalised is the way that the ICJ Programme is reported into the Regional Partnership Board.
Scope and Investment Case	AMBER	There was a defined scope and investment case to start off the programme. However, as the programme settled, it became clear, through discussion between senior stakeholders that there needed to be a change to the scope of the programme. This is reflected in the shift of the point of the start of the Cancer Journey from the moment of diagnosis to the moment of being referred for Diagnostics.
Outputs and Benefits	AMBER	Additional clarity is required concerning outputs and benefits. This work is progressing in real time as the theory of change work with the evaluation process is being completed.
Planning and Controlling	GREEN	The programme activity schedule is constantly being updated showing how the programme is developing and how the investment is being controlled.
Budget and Resourcing	RED	The budget is demonstrably well managed with updates being provided as part of the governance process. However, there is a "red" resource issue in that the Project Manager role has still not been migrated to a three-year contract and the programme lead role remains gapped although it is anticipated that recruitment will be complete by June 2021.
RAID Management	GREEN	There is a Risks, Assumptions, Issues and Dependencies (RAID) log that is reviewed monthly at the Operations Board meeting and available to the Strategic Programme Board.

Reporting and Lessons Learned	AMBER	There is a robust pathway for reporting across all elements of the programme through specialist groups to the Operations Board and onward to the Strategic Programme Board. However, there remains the requirement to develop a lessons learned log.
Delivery and Transition	RED	The onward plan for life after the Powys ICJ programme is beginning to emerge. There is a need to identify the outputs and metrics to enable final delivery of the programme and prepare for transition.

The overall rating for programme delivery was changed from amber to red to capture the issue around tenure of contracts and the high risk associated with the programme lead and project manager roles.

At the Strategic Programme Board held in February 2021, it was agreed to refocus meetings so that feedback from people who are living with cancer and the experience of front-line staff who interact with these patients could better remain at the forefront of minds during discussion and decision making. In a similar vein, the February Operational Board agreed to invite representatives from partner organisations to join this meeting to better embody the spirit of co-production.

PROGRAMME EVALUATION

Macmillan Cancer Support has made up to £50K available for the external evaluation of the programme. This is to ensure that the final model for Powys is evidence based and implemented in a way that will best serve the needs of Powys people. It is hoped that the external evaluation will enable other areas to adopt and adapt whatever is of value for them from the Powys ICJ. This will ensure more people across Wales who are living with cancer can benefit from having a conversation about what worries them most at any given point along their cancer pathway and when they would most like to do so.

At the outset of the programme, the aspiration was to procure and appoint the external evaluator as soon as possible so that all aspects of the programme - from programme set up and delivery to implementation of the pilot services themselves - could be evaluated. As part of this, the Theory of Change methodology would be used so as to describe the impact our programme would have for its beneficiaries. An early task for year 2 will be to appoint an external consultant to undertake the Theory of Change consultation prior to finalising the programme evaluation invitation to tender.

LEARNING AND DEVELOPMENT

The ICJ Programme wanted to learn and gather best practice and insights from as many other services and programmes as possible.

To broaden awareness of cancer, online training modules offered by Macmillan were attended, including Cancer Awareness, Cancer & Its Treatments, Acute Oncology: Emergency Situations and how to deal with them, Managing the Consequences of Cancer and its treatments, Personalised Care and Support Planning: Understanding the Recovery Package. A Cancer Awareness Study Day hosted by the Macmillan GP Cancer Lead for PTHB was also attended.

Examples of available literature included a number of reports that came out of the external evaluation of ICJ Glasgow conducted by Edinburgh's Napier University, a number of Macmillan publications for example, on the Recovery Package and the Wales Cancer Networks' work on optimal pathways and person-centred care. The ICJ team also learned from the programme documentation that was shared by Living with and Beyond Cancer Programmes.

The team met with staff on the ground from ICJ Glasgow, ICJ Renfrewshire, ICJ Dunbartonshire, ICJ Highlands, the Macmillan Living with & Beyond Cancer Programmes in each of Shrewsbury & Telford, Wye Valley Trust and Gloucestershire, the Macmillan Primary Care framework, the Mid Powys Holistic Needs Assessment Pilot amongst others.

Examples of key themes that have emerged include:

- There are pro's and con's to both clinical and non-clinical staff offering a holistic needs assessment. What appears to be more important than whether it is a clinician or a non-clinician, is the personal attributes of the person selected to undertake the role – it is an emotionally challenging role and the success of a service can be attributed more to the resilience and empathetic qualities of front-line staff than on technical competencies or grade.
- One model that has worked very well in acute trusts is a non-clinical support worker undertaking holistic needs assessments under the supervision of a clinical nurse specialist.
- It is worth investing the time in induction and training as well as having ongoing protected time for learning and reflection so as to support and maintain the service.
- It is important not to underestimate how long it takes to set up a service. The theme of how long it takes to set up a service has come up repeatedly, even within the context of nurse led services where the nurse had already been accustomed to undertaking paper based holistic needs assessments. In this case, the service took six months to set up.

- Services vary in how patients are identified as being eligible for receiving the offer of a holistic needs assessment. For example, automatically identifying all newly diagnosed patients, identifying patients newly diagnosed with a specific cancer type or being selected by clinicians following a multi-disciplinary team meeting (MDT). This is where several medical personnel come together to discuss a patient's care, treatment and needs.

This also means that the way in which patients receive the offer of a holistic needs assessment can vary, from...

- ✓ Receiving a letter, they had not been expecting,
- ✓ Receiving a letter, they had been expecting
- ✓ Having the offer explained face to face in clinic
- ✓ Receiving a telephone call from a support worker to offer a holistic needs assessment.

The way in which the holistic needs assessment is offered and explained has a direct impact on take up, with an automatic opt in from the National Health Service (NHS) being seen as being a best practice example. Letters can also work well as a follow up to a face to face / telephone explanation. Unsolicited letters can sometimes be problematic, with some feedback having been received around patient concern around how their details had been identified to enable them to receive the letter.

- Ensuring patients are able to choose how they wish to complete the assessment and are offered support to do so has been suggested as a best practice example.

It will be important to ensure the ongoing learning continues to feed into the development and evolution of the model for Powys.

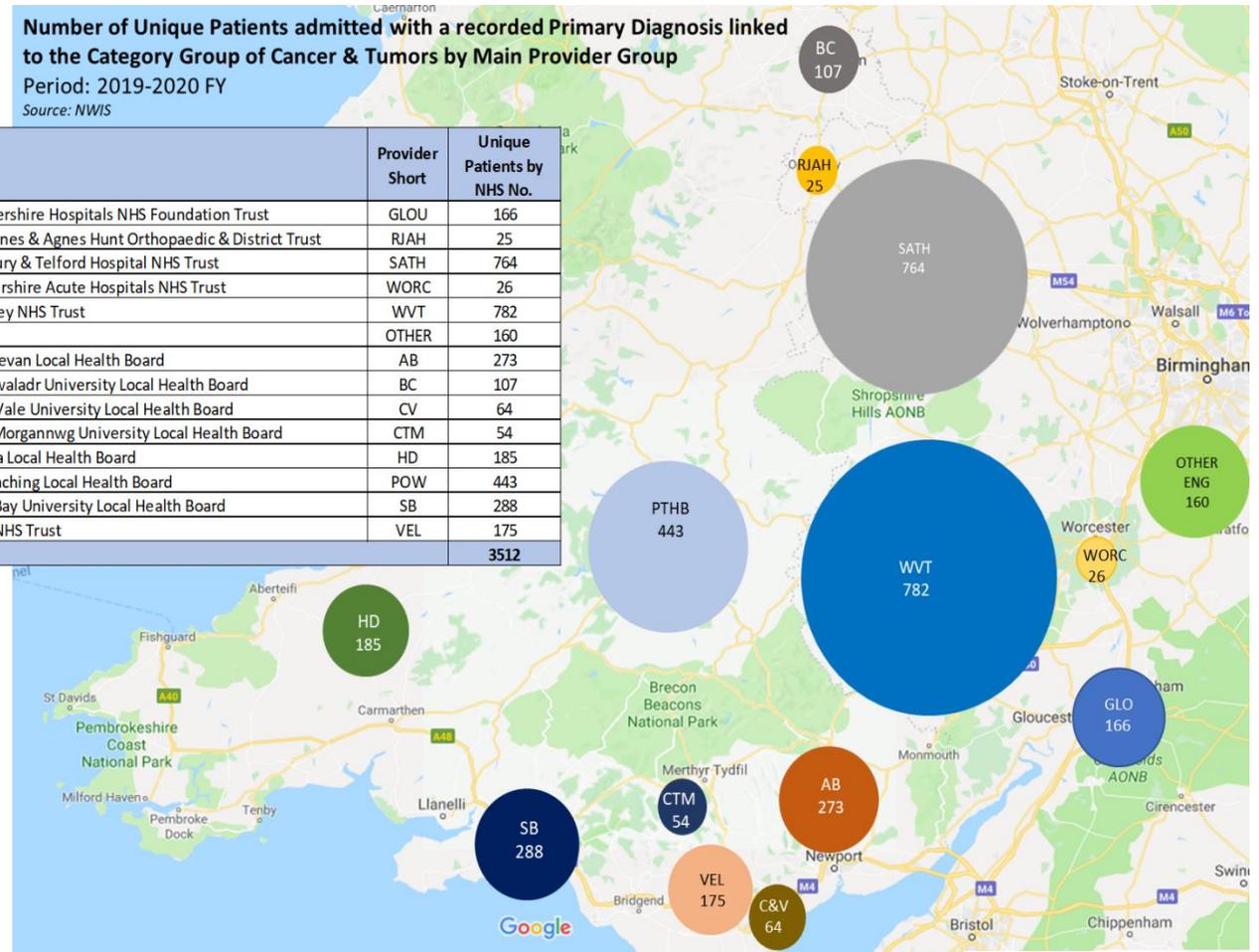
FIRST YEAR DEVELOPMENT - THE REALITY

EARLY RESEARCH AND RESULTS

While it was felt that we already knew a considerable amount about the cancer journey for Powys patients, there was a requirement to reach out to the major stakeholders engaged in the cancer journey: the patients and their support networks, the medical providers, the social care providers and the third sector provider community. Over the year, a considerable amount of effort has shed more light on these areas.

Number of Unique Patients admitted with a recorded Primary Diagnosis linked to the Category Group of Cancer & Tumors by Main Provider Group
 Period: 2019-2020 FY
 Source: NWIS

Provider	Provider Short	Unique Patients by NHS No.
English - Gloucestershire Hospitals NHS Foundation Trust	GLOU	166
English - Robert Jones & Agnes Hunt Orthopaedic & District Trust	RJAH	25
English - Shrewsbury & Telford Hospital NHS Trust	SATH	764
English - Worcestershire Acute Hospitals NHS Trust	WORC	26
English - Wye Valley NHS Trust	WWT	782
English Other	OTHER	160
Welsh - Aneurin Bevan Local Health Board	AB	273
Welsh - Betsi Cadwaladr University Local Health Board	BC	107
Welsh - Cardiff & Vale University Local Health Board	CV	64
Welsh - Cwm Taf Morgannwg University Local Health Board	CTM	54
Welsh - Hywel Dda Local Health Board	HD	185
Welsh - Powys Teaching Local Health Board	POW	443
Welsh - Swansea Bay University Local Health Board	SB	288
Welsh - Velindre NHS Trust	VEL	175
Grand Total		3512



Map sourced from Google

THE MEDICAL MODEL

Approximately 1,000 people in Powys receive a diagnosis of cancer each year and there are approximately 5,000 people who are living with cancer in Powys. While outreach to individual patients was the priority, it was also acknowledged that there was a need to engage with cancer treatment partners to understand the complexity of the Powys patients' cancer journeys.

This complexity is considerable as Powys refers all of its cancer patients out of county. This means that we have 15 primary providers of first line cancer care services.

In parallel to gaining more detailed intelligence on the medical pathway, the Powys ICJ team has also been invited to observe the Shrewsbury and Telford Living with and Beyond Cancer Programme as well as the Hereford and Worcester Programme. This observer role has provided considerable scope to see what is working with our neighbours and to learn from their experiences.

The figure on the previous page clearly shows the destination referral units for Powys patients. This serves to illustrate the complexity of tracking the cancer cohort in Powys which becomes even more complex should the patient be referred on to another specialist centre.

There are a number of ways in which a person can find out they have cancer and come under the care of an acute service:

- Via a National Screening Programme.
- A GP referral for suspected cancer.
- As a result of a presentation at Accident and Emergency.
- From other professionals such as dentists, who, during the course of performing routine treatment, may suggest that a person goes on to have further tests.

For all of these potential entry points into the Cancer Pathway, the results of diagnostic tests are returned to GPs. It is, therefore, a future priority to develop systems that will enable primary care information to be captured to enable the development of appropriate methods to track patients, their experiences, and their outcomes.

SOCIAL CARE AND THIRD SECTOR MODELS

While the Powys ICJ is embedded in Powys Teaching Health Board, social care services are a critical element of the programme. However, with COVID-19 stressing social services, it has not been possible to gather as much detail as was intended. That being said, a considerable amount of outreach was achieved and the following information is offered as a foundation for the additional outreach that will be done in 2021.

SOCIAL CARE

PCC offers an open referral system to their social care services. Referrals can be received through health or social workers; third sector organisations or people can self-refer.

The first service they are most likely to come into contact with is ASSIST. The support worker is trained to put the person at the centre of the conversation – every effort is made to take notes using the words that the person uses and

the person is recognised as being the expert of their own situation. A what matters conversation is held at this point to understand what is most important to the person. The support worker will often begin processes to help the person in the here and now. This may be signposting to services or, for example, starting the referral process for advocacy. The aim is to help the person to remain as independent as possible and support may be in the form of advice and guidance, reablement, referring to other agencies, referring to the community connectors, providing assistive technologies and so forth –

depending on what is proportionate to the reason for the call and possible at that time. If a referral into one of the services for adults is made, these services will then carry out a holistic integrated needs assessment with the person.

The ICJ Team have met with and presented the programme to the Adult Services and Commissioning Senior Management Team and to a number of operational managers, such as for Older Peoples Services, ASSIST, Reablement and Inhouse Domiciliary Care and Occupational Therapy.

The purpose of these meetings was to raise the awareness of the Powys ICJ Programme, to better understand how social care services interact with people who are living with cancer and to understand what the opportunities for working together might be. This was at a time when services were still struggling with the impact of Covid and the ICJ team is grateful for the time managers have put in to these meetings. Every manager that we have spoken

with has indicated that our aspirations to offer every person who is living with cancer a supported conversation using the holistic needs assessment is entirely in line with their own work to ensure clients have a stronger voice and greater control over what support they receive so they can achieve what matters most to them. It also fits with their work to ensure timely advice and support is given so as to prevent things from reaching a crisis point. Every manager indicated that, if a person living with cancer contacted their service and had already had a holistic needs assessment, they would find value in being able to see this as well as the care plan.

These meetings also highlighted to us some of the challenges faced in sourcing domiciliary care and providing support at home in rural Powys and the importance of timely home adaptations when required. Work is being undertaken to by the services to support people differently and to enable easier access to care and support when needed.

THIRD SECTOR

In Powys, there are over 4,000 voluntary or third sector organisations. PAVO is the Powys Association of Volunteer Organisations. It is a membership organisation open to all third sector organisations and groups and Town and Community Councils in Powys, all working to meet the needs of people and communities across Powys. PAVO have over 730-member organisations and are in regular contact with over 1500 organisations. The Bracken Trust, Credu, Macmillan Cancer Support and PAVO are third sector organisations who are all represented on our Strategic Programme Board.

During this first year, there have been meetings with a number of third sector organisations such as Bracken Trust, Credu PAVO's Community Connector and Befriending Service, PAVO Volunteering, St David's Hospice,

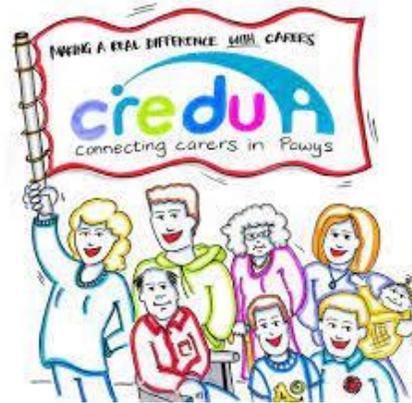
Marie Curie, various representatives from Age Cymru, Maggie's in Swansea and the National Exercise Referral Scheme. Meetings have taken place with PAVO's Senior Officer on a monthly basis and the ICJ team has attended a number of PAVO's monthly locality meetings and Credu's carers forums. The purpose of these meetings was to raise awareness of our programme and to better understand what these third sector organisations do so that we could begin to understand what may be available locally to serve the needs of Powys people who are living with cancer. PAVO's community connectors pulled together a list of services which might be of interest to people who are living with cancer and this made the ICJ team aware of services such as the Inspire Welshpool Cancer Support Group, Byw'n Dda Machynlleth Living Well, Impelo and the Tenovous Choir.

With the sheer number of services, many of which have defined areas that they serve within Powys and some of whom are only funded for a fixed term, the landscape is undeniably rich and complex. Directories of services do exist in the form of Infoengine, Dewis and Cancer maps but it can be difficult to find a service in this way unless you know exactly what it is you are looking for.

PAVO and CREDU are both well placed to remain abreast of, and to communicate, what is available through the monthly PAVO Community Connector led meetings across the 13 localities of Powys. These meetings are attended by a range of local services and interested parties and it provides an opportunity for those in the area to share updates around what is going on and to address gaps in provision.



PAVO's community connector service is well regarded.



Credu – caring for carers who are supporting loved ones with a diagnosis of cancer.



The Bracken Trust supports over 300 people living with cancer in the county.

COVID-19

While this is a cancer programme report, the impact of COVID-19 on the medical and social care landscape has been profound and will be long lasting.

From the patient perspective, there is considerable evidence already being discussed about the impact that COVID will have on cancer patients from delayed diagnosis (due either because people did not attend their GP with their symptoms or the difficulty in accessing diagnostic services) or interrupted treatment pathways.

In addition, social care services have also been focussed on COVID related issues and the third sector has adapted its services during the Covid climate in order to continue providing support to their clients.

**MACMILLAN
CANCER SUPPORT**



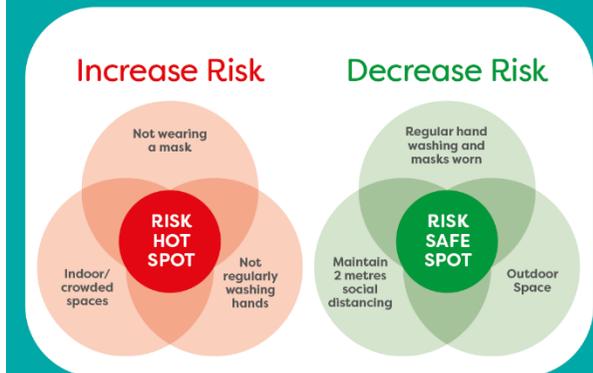
SELF ISOLATE

Stay home if you or someone in your household have symptoms, or if you're asked to by a contact tracer

Powys DIOGELU CYMRU
KEEP WALES SAFE

The infographic features a teal background. At the top, a white icon shows a person standing inside a house, with a virus particle nearby. Below this, the text 'SELF ISOLATE' is written in yellow. The main message is in white: 'Stay home if you or someone in your household have symptoms, or if you're asked to by a contact tracer'. At the bottom, the Powys logo and the 'DIOGELU CYMRU KEEP WALES SAFE' logo are displayed.

Covid 19 - Know The Risks



Together we'll keep Wales safe
gov.wales/coronavirus

PROGRAMME EVOLUTIONS

Electronic Holistic Needs Assessment (e-HNA). At the start of the programme, while it was acknowledged that there would be a need to deploy a single, transferrable, patient owned holistic needs assessment methodology; the detail was not decided. Over the course of the year, the Macmillan eHNA has become the model that is being rolled out. Third sector providers have already completed the necessary Data Processing Agreements with Macmillan while PTHB is in the process of completing the process. The adoption by all stakeholders of this tool will enhance information collection and sharing and will help avoid duplication of effort or, worse, gaps appearing in the range of support services being offered to Powys patients.

Diagnostics. At the start of the programme, diagnostics was not seen as part of the cancer journey as such in that the Journey was seen to start after the diagnosis had been made. However, as a result of the disruption to cancer services caused by COVID-19 and influenced by the need to align with the principles of prudent and value based health care, it has been accepted that the cancer journey starts with the patient presenting to their GP for onward referral for diagnosis. Quite how this evolution will be integrated into the programme plan is still to be detailed.

Patient Tracking. One key component of the cancer information requirement that has been mentioned by all stakeholders is the problem, related to the complexity of the Powys medical model, of how to track the patient cohort. With Powys sending the majority of its patients outside the county for initial assessment, diagnostic, and treatment planning, it has not yet been possible to track accurately Powys patients on their cancer journey. This is having an impact on how we track outcomes and plan services along the whole pathway from diagnosis to end of life care. While the focus for this work lies within the PTHB cancer transformation programme, it has an impact on the Powys ICJ programme.

Leadership. There has been considerable change in the leadership of the ICJ programme within PTHB;

- In July 2020, the Medical Director (MD) retired and an interim in place until the appointment in February 2021 which ensures future continuity.
- In Dec 2020, the ICJ Programme Lead left for a new role. Until a new Programme Lead is in place, the day-to-day management of the programme has been vested in the PTHB Assistant Medical Director. The new programme lead starts in June 2021.

HIGHLIGHTS OF THE FIRST YEAR

While a lot has been achieved in the first year, and done so in very challenging circumstances, two activities in particular should be mentioned in greater detail:

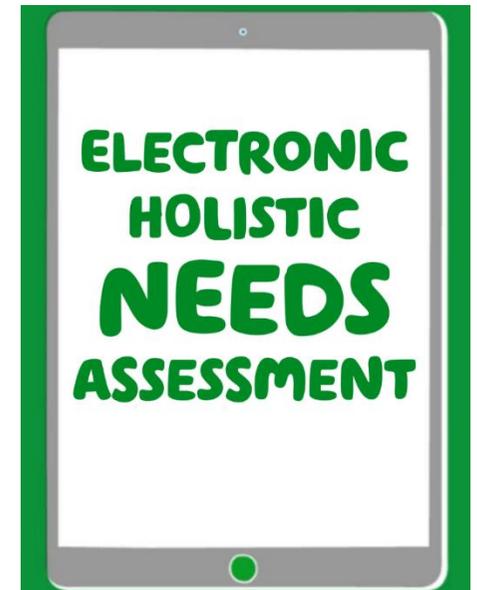
- The development of the ICJ Holistic Needs Assessment Offer
- Understanding the patient experience.

DEVELOPING THE ICJ HOLISTIC NEEDS ASSESSMENT OFFER

One of the first things learned was that, while it is known that around 1,000 people in Powys are diagnosed with cancer each year, the Health Board does not, in real time, know who these people are, where their pathway is taking them and what their experience is. ICJ Glasgow had a way of identifying patients and writing to them so that they could receive the offer of a supported conversation. A priority, which fits in with a wider information quality initiative within PTHB will be to develop a system that will enable the tracking of the cancer cohort from first referral onwards. This will also help PTHB understand where there might be inequities in service delivery, experience, and outcome. In addition to this poverty of healthcare information. It was also noted that there was an inequity in how ongoing needs were assessed and planning done to put holistic care packages in place.

Conversations have taken place between the ICJ team and some of PTHB's acute providers focused on the offer of Holistic Needs Assessments and how we might forge links between local services that acute trusts could refer in to following care planning. This later evolved into conversations around developing a local model to offer the holistic needs assessment with the understanding that this would build on an asset-based community development model.

As Macmillan already has a needs assessment tool available, it has been a logical step to use this resource from the outset. Setting up to be able to offer Macmillan's electronic holistic needs assessment (eHNA) has since become a major element of the ICJ programme as more stakeholders have come forward to embrace the eHNA tool.



INITIAL DELIVERY STAGE

The initial delivery strategy set out a sequential, staged approach with the first year to have been based upon research, learning and engagement – gathering information around what is already taking place and gathering rich insights from stories from people who are living with cancer– that would then inform the creation of pilots in stage two and ultimately lead in to the development of the business case for the preferred model in stage three.

With the programme officially paused due to COVID, the team continued to progress ICJ activities where possible but it was not able to meet with service providers to understand what was already taking place, how COVID was affecting service delivery and what the future model might look like. While COVID-19 certainly interrupted service delivery, it also appears that the landscape is changing permanently introducing a new requirement to

understand what the “new normal” will be. For example, the expansion of the use of digital technology to deliver remote consultations has certain advantages when it comes to addressing the challenges of rurality. However, it must be remembered that the digital change does not mean that face to face consultations can be dispensed with.

As the programme emerged from the first wave of COVID and in the lead up to the relaunch of the programme, consideration was given to how the programme deliverables have changed over time. This has led to a slight revision of outputs and timelines with some areas of work having progressed even during lock down (understanding the medical pathways) and other, obviously not having progressed as well; in particular, the work that required more personal conversations.

INPUT FROM PEOPLE WHO ARE LIVING WITH CANCER

The Communications & Engagement Strategy that had been signed off by the Strategic Programme Board set out the intention to run a survey to capture patient experience however there were a number of factors that were readily recognised that made gathering patient experience of having been offered a holistic needs assessment problematic:

- It was known from conversations around the county that many plans or existing arrangements to offer holistic needs assessments had been put on hold as staff were redeployed into clinical service delivery. Because of this, we understood that any patient with a very recent experience of acute care would more than likely not have been offered a holistic needs assessment.

- The terminology may be confusing for patients – some patients may report that they have been assessed holistically because they may have been asked a number of questions by nurse’s who are trained to assess patients holistically. Yet, this isn’t what the ICJ means by a personalised care plan driven by a patient owned holistic needs assessment where the patient sets the agenda for the conversation. Other patients, we know, may not understand that they have been offered a holistic needs assessment and say they’ve not had one when in fact they have.

- Holistic Needs Assessment is an existing, established, evidence-based activity that can be used in many ways. For example, we know of GP surgeries in Powys who send a version to patients, once they have been discharged from hospital - a paper-based Macmillan Holistic Needs Assessment. This may represent a good service for the patient but, again, would not be what ICJ means when we survey to ask people who are living with cancer whether they were offered a holistic needs assessment during their treatment.
- There are also many other forms or surveys that patients may have been asked to complete and which may easily be confused with a

holistic needs assessment although the reasons information is sought for a HNA is distinct. Examples include PREMs (patient reported experience measures,) PROMs (patient reported outcome measures) and the AIA (adult inpatient assessment) that has been rolled out across Wales. Clarity is required in getting patients and providers to understand the importance of each.

- Finally, Macmillan were working on the next iteration of the Patient Experience Survey so timing was considered a factor in choosing to capture patient stories but not through a survey methodology.

PLANNING THE PILOTS

In late 2020, colleagues in the Health Board, Macmillan, PAVO and Credu agreed to put forward ideas to develop eHNA pilots involving the Health Board's Specialist Palliative Care Team, the Bracken Trust and, thirdly, around PAVO working in partnership with Credu and potentially linking in with one or two Powys GP surgeries.

Macmillan colleagues shared their plan on a page format which was used to shape initial discussions, obtain agreement and understanding with the ICJ Programme Manager. These discussions led to a suggestion that this methodology could be tweaked to support the development of the pilots and a template subsequently adopted. The template allowed pilot partners to set out their vision, scope, outputs, benefits, risks, and outcomes in a simple format.

IMPLEMENTING THE PILOTS

In late 2020 and early 2021, the ICJ team met with pilot leads on a number of occasions to further discuss the pilots and for Macmillan to demonstrate the eHNA tool to each pilot organisation. Once pilots are set up to offer electronic holistic needs assessments, the intention is to evolve them further with more integrated pathways and information sharing agreements to enable the patient to experience a seamless service. PAVO has put forward the idea of working together with Credu and a couple of local GP practices so that GPs can refer into the service. There is a particular interest in being able to know and to see the content of recent holistic needs assessments that may have been conducted elsewhere, such as in other acute trusts, so as to avoid duplication.

- **The Bracken Trust**

The Bracken Trust has signed Macmillan's Service Provider Agreement for their electronic Holistic Needs Assessment and all registered nurses have received training. Alongside getting their administration processes in place, the Trust has subsequently been offering electronic holistic needs assessments to all its caseload since going live in February 2021.

The Trust had been using the Macmillan paper based Holistic Needs Assessment for its patients for a few years and therefore Trust staff were in a good position to extend the process electronically. Since going live, they have been offering electronic Holistic Needs Assessments to all new patients who have not had one completed elsewhere.

They also use the Carer Support Needs Assessment (CSNAT) evidence based tool which facilitates tailored support for family members and friends (carers) of adults with long term life-limiting conditions.

- **Powys Teaching Health Board (PTHB)**

The ICJ team and Macmillan presented the electronic holistic needs assessment system to the health board's ICT Governance Group in December 2020. The ICJ team worked with Macmillan's eHNA Digital Product Owner, PTHB's Macmillan Lead Nurse for Cancer and Palliative Care, and PTHB's Information Governance Team to ensure compliance with the relevant legislation and internal processes.

PTHB's Specialist Palliative Care team has been trained on the system and plan to begin offering electronic holistic needs assessments in the North of Powys following Executive sign off. The North Powys team is already accustomed to offering holistic needs assessment, using Macmillan's paper-based tool. Alongside this, the PTHB Specialist Palliative Care team are working with the IT department and with Macmillan to develop an application for a support grant to fund tablets to enable face to face and remote electronic holistic needs assessments to be offered.

- **Credu and Powys Association of Voluntary Organisations (PAVO)**

Both Credu and PAVO have now been added to the Macmillan electronic holistic needs assessment system and both organisations aim to go live around May 2021 with training and implementation plans being developed with Macmillan. (At the time of finalising this report they had both gone live).

- **Powys County Council (PCC)**

PCC have also expressed an interest in participating but developing this interest will be a task for year 2.

Additional support offered

PTHB's Lead Nurse for Cancer and Palliative Care also offered training to anyone in the pilot organisations on the physical needs that cancer patients may raise in the follow up conversations having completed the eHNA. Credu has offered training to all pilot organisations on collaborative communication so as to better reflect upon and draw out patient needs. As each pilot brings a different specialism to the table, it is expected that each pilot will deliver a different directory of services. For example, Credu and PAVO may have a far more detailed understanding of local third sector services than, for example, PTHB's Specialist Palliative Care team. However, the specialist care team will have a better understanding of clinical service options.



UNDERSTANDING THE PATIENT EXPERIENCE

In January 2020, a workshop bringing together all the partners established the over-riding vision, mission, aims and objectives for the programme. A two-stage stakeholder mapping exercise identified who would be affected by and who would contribute to the programme, followed by consideration of their communication and engagement needs so as to keep all parties involved, engaged, and informed as the programme developed.

IMPROVING THE CANCER JOURNEY IN POWYS

Our Vision
That everyone living with cancer in Powys gets the right help and support to achieve what matters most to them.

Our Mission
To improve the experience and the quality of life for people living with cancer in Powys by enabling access to, and coordination of, personalised physical, practical, emotional, spiritual and social support.

Aim and Objectives
To develop a sustainable, supportive, integrated community model of care to support people living with cancer in Powys.

How we will do this? We will:

- ✓ Develop a deeper understanding of issues and experiences for residents* of Powys
*Note: *Residents means people aged 18+*
- ✓ Hold ongoing conversations with those living with cancer via various engagement events/multi-media resources
- ✓ Establish a cross section of health, council and third sector staff perception of issues and experiences for residents diagnosed with cancer in Powys
- ✓ Based upon the information gathered, trial and evaluate a number of approaches

Want to find out more?
e: ICJPowys@powys.gov.uk




Improving the Cancer Journey in Powys Programme

Stakeholder Map Stage One:

Build on current knowledge and understanding of the needs of Powys residents living with cancer.

The first phase when considering the stakeholders is to split them into two groups
- those who will be **affected** by the programme/project
- those that will **contribute** to its success

NOTE:
Some stakeholders fit into both categories. For example people living with cancer will be contributing in this stage by sharing their stories to aid understanding about the current post diagnosis support they receive, but they will also be affected by the outcomes in terms of the model of care that is developed for Powys.

Affected by...

- People living with cancer (including their families and their carers)
- PLUS...**
- Macmillan professionals
- PCC professionals (working in social care, housing, benefits, libraries etc.)
- Health professionals
- Third sector/voluntary organisations (PAVO, Credu, Age Cymru, Mind, Bracken Trust etc)
- Macmillan volunteers
- GPs
- Welsh Government
- Wales Cancer Network
- Community Health Council
- Other parties - e.g. employers / trade unions / residential and nursing homes

Contributes to...

- People living with cancer (including their families and their carers)
- Macmillan
- Powys County Council
- Powys Teaching Health Board
- Powys Regional Partnership Board
- Powys Public Service Board
- Project Sponsors
- PLUS...**
- Media (local and Welsh)
- Politicians (local and national)
- Wales Cancer Network
- LWBC projects
- Other parties - Freedom Leisure

In partnership with **MACMILLAN CANCER SUPPORT**



Improving the Cancer Journey in Powys Programme

Stakeholder Map Stage Two:

Build on current knowledge and understanding of the needs of Powys residents living with cancer.

The second phase is to consider what level of interest and influence the different stakeholders may already have or should have in relation to the programme/project outcomes in Stage One and then categorise them accordingly. There are four headings to consider. This analysis ensures that all stakeholders are involved or kept informed about progress at the right time, in the right way with information that is relevant to their needs and their role within the programme. Some may feature in more than one quadrant.

Keep Completely Informed

- People living with cancer (including their families and carers)
- PLUS...**
- Macmillan professionals
- PCC professionals (working in social care, housing, benefits, libraries etc.)
- Health professionals - (PTHB, DGHS)
- GPs
- Third sector/voluntary organisations (PAVO, Credu, Age Cymru, Mind, Bracken Trust etc)
- Powys Community Health Council

Manage Most Thoroughly

- Powys Regional Partnership Board
- Macmillan professionals
- Community Health Council
- Third sector/voluntary organisations
- PLUS...**
- Media (local and Welsh)
- Politicians (local and national)

Regular but minimal contact

- Macmillan projects supporting the ICJ Powys Programme
- Macmillan volunteers and ACP champions
- Voluntary projects supporting the ICJ Powys Programme
- All PCC & PTHB employees

Anticipate and meet needs

- Powys Public Service Board
- Project Sponsors
- PLUS...**
- Media (local and Welsh)
- Politicians (local and national)

Level of interest ↑

→ Level of influence



CANCER CONVERSATIONS

As key stakeholders and in the spirit of co-production, the past year has been focused primarily on capturing and listening to the views and experiences of people living with cancer in Powys to try and establish a clearer picture of what their cancer journeys entail when living in a rural county.



These conversations have provided rich insights about where, when, how and what services have been offered to people following a diagnosis, what support people want, what appears to be lacking or missing and what support people manage

to access for themselves. Prior to Covid a detailed Equality Impact Assessment was completed which placed a particular emphasis on trying to reach out to those people living with cancer who might be unable to engage via typical methodologies.

It was originally planned and acknowledged that there would be a requirement to go “door to door” travelling around the county harnessing community links and attending various events, forums, or meetings so as to have a face-to-face dialogue listening to people’s experiences and stories in their own settings.

However, due to lockdown, shielding and restrictions it became evident that capturing these stories would require a different approach – a “call to action” primarily using social media channels and relying on key partner connections to encourage people living with cancer to get in touch and share their cancer journey pro-actively.

WHAT WE ALREADY KNEW

The Wales Cancer Patient Experience Survey is a strategic collaboration between Welsh Government, Wales Cancer Network and Macmillan Cancer Support. In the last Wales Cancer Patient Experience Survey, conducted in 2016, 263 Powys residents who had received a cancer diagnosis and treatment were invited to give their views so as aid understanding around the whole patient experience. Just over 70% (173) responded to the survey.

Overall Powys residents gave high praise for the quality of care and the timeliness of the treatment they’d received following a diagnosis. The vast majority were also appreciative of the thoughtfulness and professionalism of staff involved in their treatment. However, there were also comments around the lack of care at home once coming out of hospital, people feeling quite isolated in between appointments and not knowing where to go for support. The other topic that is very relevant to a rural county without a

District General hospital was travel and how this impacted upon and was challenging for patients.

To sum up, the key findings were:

- 98% received information in their preferred language
- 97% felt that their GP had been given all the necessary information about their hospital stay
- 90% rated their overall cancer care as a 7 out of 10 or more.
- Less than half (45%) felt that they had been able to completely discuss the impact of cancer on their day-to-day activities
- Only 41% felt that they’d received information about financial help or benefits
- Only 15% were offered a written care plan

WHAT WE'VE LEARNT IN THE PAST YEAR

During the first year of the ICJ programme, the experiences, and stories of over 40 people have been heard through a variety of channels from individual telephone calls through to an online focus group and the establishment of a specific Journeying Together Forum. Alongside this, partners and advocates have also shared stories of people they've supported over the past year.

Four years on from the 2016 Patient Experience Survey, there are a number of similarities emerging from the people who have been in touch. The vast majority are satisfied with the care and support they receive when in a hospital setting whether this is from a nurse, an oncologist or consultant. Some comments emerged around the differing communication styles of the professionals giving a diagnosis. For some the manner could be improved and was seen as sometimes quite clinical and lacking empathy. District nurses were seen to be offering a good service in the county although there was some confusion about their roles. Overall, there were some clear indications that the same confusion reigned in relation to the co-ordination and access to social health and care service offered by both the council and the health board following a hospital discharge.

For those residents who had received a diagnosis since 2016 it appears that most had, in their view, received prompt attention with referrals for tests being swiftly organised. There has been a strong feeling of gratitude for the medical profession and the care given by oncologists, consultants and in particular nurses. Since lockdown several felt they had received prompt attention with minimal delays to their treatment pathway. One person commented that in her view the hospital appointment had been less stressful, that she'd felt she'd been given the full attention of the nurse allocated to be with her and the experience had been better than before the pandemic. However, there were a couple of incidents where Covid had led to a delay in a person seeing their GP or where treatment had been postponed due to the pandemic.

From all the conversations had, only three people who got in touch, could state that they had definitely been offered a holistic needs assessment either by the hospital trust managing their treatment or by another organisation based in the county. For one person this offer had come from their hospital trust but it was a retrospective invitation to complete the HNA a year following their diagnosis. For another person, the offer was welcomed and proved beneficial whilst for another it had helped them to consider their personal circumstances and reach the conclusion that actually for them, they did not want or need any additional support. Overall, ten key themes have emerged from the patient stories. There were some additional themes that came out from the conversations including inequality around some of the cancer treatment pathways, technology advancing care, the environments that support people living with cancer, employment, and well-being.

LISTENING TO PATIENT STORIES KEY THEMES

1	Pre-diagnosis, diagnosis and prognosis	
2	Co-ordination of Care	
3	Emotional Support & Care	
4	Patient Voice and Choice	
5	Carers Rights and Voice	
6	Practical Support offered in the county	
7	Relationships and communication	
8	Transport and Travel	
9	Education and Information	
10	Advance Care Planning	



Bwrdd Iechyd
Addysgu Powys
Powys Teaching
Health Board





1. PRE-DIAGNOSIS, DIAGNOSIS, AND PROGNOSIS

Although the original scope of the ICJ programme was to consider what support is given to people following a diagnosis, the stories that people have shared about their cancer journey begin prior to diagnosis with initial worries about possible symptoms or a screening appointment, the visit to their GP, the fear, the wait for appointments, the tests and more tests before a diagnosis can be given.

Most people had had good experiences whereby their initial concerns prompted immediate referrals and subsequent timely tests and a diagnosis which was explained in a clear and tactful manner. For others, the experience was more negative with some GPs appearing unsure or reluctant to refer patients for tests in the first place, whilst for others the delivery of the diagnosis and subsequent information about what to expect was unclear and poorly communicated. For one person not understanding what her husband's "palliative" diagnosis meant led to a missed opportunity for support.

"I was lying there thinking what are you saying to me? If it's cancer just say it's cancer."

"I felt angry for quite a long time about our experience and the effect it had on all the family."

2. CO-ORDINATION OF CARE

"I received extremely prompt action from my GP surgery. There have been no delays in spite of the difficult circumstances due to Covid-19."

"It's so confusing the threshold for eligibility and care and support based on the prognosis given. There was lots of chasing going on to find out what support was available in county."

Feedback from people living with cancer clearly suggests that there is work to do to better co-ordinate, communicate and clarify the roles and remits that exist between all the services who should be, or could be involved in supporting a person living with cancer following a diagnosis. This resonates with some of the qualitative feedback from the 2016 survey.

It was acknowledged by nearly all of the people who shared their story that the offer of a holistic needs assessment would be welcomed and help to significantly improve the support they received following a diagnosis.

For the most part people appeared to have had a good experience in terms of the first part of the pathway from referral to diagnosis and treatment but the co-ordination of care appeared to fall down for some once discharged from the hospital setting.

Several people were left feeling unclear about where to get support in the county and their eligibility to do so. The need to be proactive and spend time regularly chasing up different people and organisations in an attempt to receive information, services and support whilst still managing with the after-effects of surgery and the emotional scars was both tiring and frustrating.

"I was really surprised that my annual check was taking place hearing that appointments were being cancelled or postponed due to the pandemic."

3. EMOTIONAL SUPPORT AND CARE

This came out as a strong theme and in particular the consideration of peer support within the community so that following a diagnosis if people wanted to, they could talk to someone else locally who understand their situation/cancer and what they were going through. With Covid the Macmillan telephone buddy scheme was an alternative option.

“You feel anxious and scared and vulnerable. It completely changes your life. You lose your sense of self, your identity and worry about the cancer returning.”

Some residents had set up their own support group, some had the support of a specialist nurse in the hospital and some had accessed information and support online.

Counselling support was seen by many as crucial to helping to come to terms with a diagnosis and what and how to manage feelings around “why me?” and “how long have I got to live?”

The Bracken Trust was noted as an excellent provider of such services by several people and had significantly improved their mental resilience and well-being as a result.

“In my view everyone should be offered counselling following a diagnosis of cancer - even following successful treatment.”

4. PATIENT VOICE AND CHOICE

For the most part it appeared that professionals in both primary and secondary care were respectful and listened to patients views around their initial health concerns, their diagnosis and their treatment plans and choices.

However, this wasn't the experience of everyone who shared their story. Some residents felt that their GP and some practice nurses had been quite dismissive when first raising their concerns about their own health which subsequently did cause delays in diagnosis and treatment. For a few people seeing a locum instead of their actual GP had, in their view, proved more beneficial to accessing treatment and being listened to.

There were some instances whereby people weren't really clear about their treatment choices and had had a diagnosis but no real insights into the options that might exist for treatment. For others this had been clearly explained.

In relation to terminal diagnoses being able to respond to patient wishes was not easy on all parties. Although evidence suggests that people would like to die at home, families are not always in a position to know how to care for said person and as already mentioned accessing “end of life” care can be difficult. If advice is given that the best place might be hospital, this can often be the choice the family make even if the person with the diagnosis has a different view and wants to die at home.

“What if I hadn't of seen a locum?”

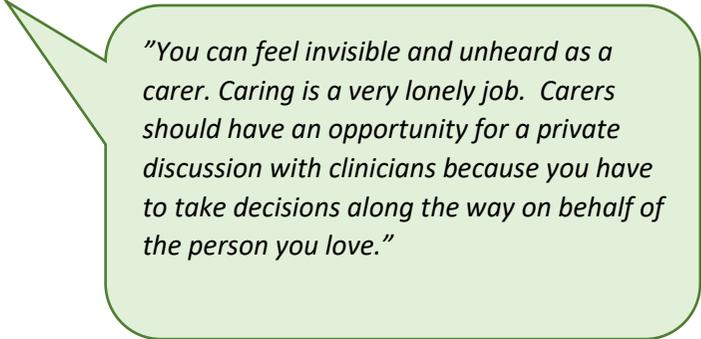
“My mum didn't want to be in hospital – she wanted to die at home.”

5. CARERS RIGHTS AND VOICE

For family members caring for the person diagnosed with cancer, there were comments around the feeling of being worried on their behalf, being unsure what was happening, being invisible and ignored in clinical settings where the oncologist spoke directly to the patient but didn't seem to acknowledge their loved one.

With Covid there was the added worry for carers in that they could no longer support their loved one as they had to attend appointments alone. This could leave them feeling somewhat out of the loop and also place pressure on the person with the diagnosis to remember and share all the details given.

Recording the consultation was one solution offered up which allowed family members to understand exactly what had been said.



"You can feel invisible and unheard as a carer. Caring is a very lonely job. Carers should have an opportunity for a private discussion with clinicians because you have to take decisions along the way on behalf of the person you love."

6. PRACTICAL SUPPORT OFFERED IN THE COUNTY

In relation to services and support available to people within the county once they had received a diagnosis there were mixed views and experiences given. For some their whole support came from family members or friends, or both, and there was no desire or need to access any additional services that may be on offer. For others, the offer of some local support would have been appreciated where none was forthcoming. There were comments about feeling "let go" and left to get on with life either in-between treatment sessions or when treatment had finished and the person was discharged or told they'd get a check-up in six months or so.

At these times, the lack of or limited contact left people feeling somewhat forgotten and abandoned. Some patients were referred via their GP to a service whilst others did their own research to find out where they might get help. Those who had proactively sought help and support for themselves had contacted a variety of services within the county including the district nurses team, the welfare benefits team based at Powys County Council, the Bracken Trust, the community connectors (PAVO), Care & Repair and also the Assist service – the council's Adult Services referral front-door service.

Some of these experiences had resulted in positive outcomes with patients receiving benefits, blue badges, counselling, complementary therapies, care, and adaptations to their homes.



"Having the offer of a Holistic Needs Assessment at about six weeks would be good. It's extremely difficult to think about everything you need to think about from financial worries to how to explain to children what's happening."

For others confusion ensued around expectations and capacity for help from both the primary care and social health and care professionals in particular when being discharged from a hospital trust back to county.

Eligibility for personal or domiciliary care and understanding at what point in time this would be offered and who was responsible for the provision of said care was seen as an area of concern by many.

A “too little too late” comment was made more than once.

For those who were more digitally aware, accessing Macmillan’s website, helpline, and online chat groups proved helpful. One family had finally managed to access support from St David’s which was deemed as excellent with the nurse staying overnight with their loved one.

7. RELATIONSHIPS AND COMMUNICATION

In terms of relationships and communication there were obviously different styles and approaches used by those involved in referring people for tests and those determining the outcome and sharing the diagnosis news. From the stories shared there appeared to be both good and bad examples and experiences around relationships with GPs, oncologists, consultants etc.

For the most part nurses were seen to be the people who communicated the best and were more conscious and empathetic towards patients’ needs and feelings.

The role of the GP and how they communicated with their patients was raised by several people. Again, some GPs were excellent in listening to patient’s concerns. The key gap was seen to be the lack of a link back from the hospital to the GP following a diagnosis and treatment and then from the GP back to their patient.

“People didn’t know how to react to the news that I had cancer or what to say. People shied away.”

“I was in complete denial and the specialist urology nurse was wonderful – helping me to unpick my emotions.”

There was a clear desire for people to have more regular contact with their GP keeping a dialogue going in between and following treatment. Many talked about the “traditional GP service” being wanted and needed especially in a rural county like Powys. For some there was an obvious change in the way that others reacted to them although for the most part family and friends were very supportive. Again, one carer noted that her husband “clammed up” following his diagnosis. For another person, her husband and children were ready to “brave the shave” in support as she began her treatment.

Support and relationships at work was also a topic raised by a couple of people. Overall work colleagues were seen to be supportive, as were managers. One resident who was due to retire had been kept on by his employer whilst he had treatment and went back to work. Another resident however, had had to have a month off and was pressurised to return to work. She didn’t feel supported and subsequently left her job.

8. TRANSPORT AND TRAVEL

A tricky element for Powys residents and something that all have to face is the need to travel out of the county for treatment. For the most part those who shared their story accepted this. However, where feasible, there did seem to be scope for some improvements to be put in place both in hospital trusts dealing with Powys residents and in county around the appointment times and co-ordination of scans and follow up appointments.

“Surely it makes sense to try and co-ordinate patient needs especially when travelling from Powys. Reducing journey times would be helpful.”

One lady had been told she needed both an MRI scan and a CT scan – both at the same hospital. However, she ended up having to go on two separate dates even though she’d raised it as an issue and asked if there was scope to travel once. For another patient access to non-emergency transport proved very stressful. Cancelled transport, poor routing decisions, a rude driver and being given the run around was her experience.

For others, reducing unnecessary travel was something they’d like considered more alongside hospitals recognising that travel times for Powys residents should be a factor in allocating appointment times. GP surgeries being aware and mindful that some cancer patients receiving treatment needed blood tests on specific dates and giving them priority over less urgent blood tests would be useful. One lady who was having chemotherapy had been told there were no appointments left even though she’d rung up two weeks in advance.

9. EDUCATION AND INFORMATION

“It can sometimes feel quite impersonal and having someone check that you understand what your treatment is and why and being asked how you feel about it is lacking.”

Getting the right information following a diagnosis of cancer was seen as really important so as to allow people to reflect, consider and make the choices that were best for them. This ‘information giving’ links strongly to the theme of Patient Voice and Choice. Similarly, educating all those involved in patient care as well as the patient themselves was deemed of equal importance.

There were some examples whereby the GP, the clinician, oncologist, or consultant hadn’t been very clear about the potential prognosis, the next steps in the treatment pathway or what options might exist and what to expect afterwards.

“I was told I’d get some leaflets in the post but these never arrived. They emailed them to me instead which might have been the best option in the first place.”

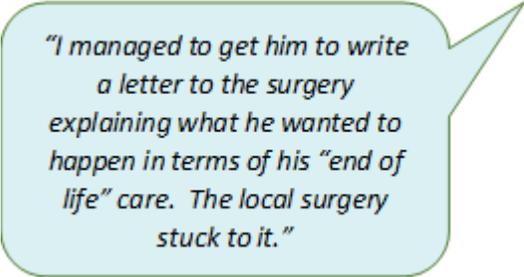
Some people wanted all the details and were keen to understand the complete pathway whilst for others just getting their head around the initial diagnosis and receiving information about this would have been enough. The delivery of the diagnosis and having to wait for the next appointment to find out more was quite stressful for some alongside not really knowing what questions to ask. A couple of people felt unclear about what their diagnosis meant and had not been offered any information and had then had to wait for a follow up conversation – sometimes waiting a week or so in between before being given a clearer idea about treatment.

10. ADVANCE CARE PLANNING

A couple of people had initially been told they didn't have long to live and then subsequently received treatment which changed their prognosis for the better. There was some suggestion that although it was shocking to hear the news that you have terminal cancer, most, but not all, felt they had been sensitively dealt with and could plan ahead based on their prognosis.

One person said knowing his mother only had a short time left allowed them to plan and take her away for a short break.

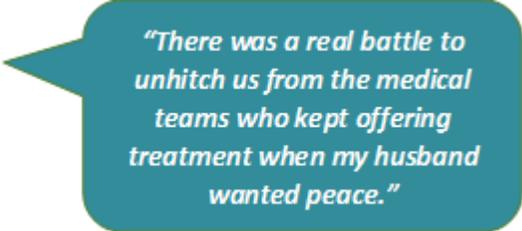
Carers in particular felt they were left trying to manage as best they could, supporting their loved ones and trying to ensure their wishes were considered.



"I managed to get him to write a letter to the surgery explaining what he wanted to happen in terms of his "end of life" care. The local surgery stuck to it."

For one person the topic of quality of life versus continuing treatment was something they felt needed acknowledgement by the medical profession.

For another family trying to access some personal care for their mother proved very stressful. There was a feeling that because they were just about coping, they were left to it and support finally offered was too little too late. The day it was due to be in situ was the day the patient died.



"There was a real battle to unhitch us from the medical teams who kept offering treatment when my husband wanted peace."

OTHER THEMES

Some other themes that were not as common but worthy of a mention included the environment that people being diagnosed with cancer were being exposed to. A calm and pleasant setting with consideration of seating and friendly staff could make all the difference to how a person felt when attending appointments whether on the way in or out.

A positive topic that emerged from conversations was around people's resilience and ability to enjoy hobbies and life following a diagnosis. Known as post traumatic growth a few people shared how they had "turned their life around" or embraced hobbies such as art or craft making and how this supported their well-being.

The advancement of technology was a key factor in one person's quality of life. Having been fitted with a Portocath system to deliver chemotherapy meant that this person had been able to travel abroad for two memorable holidays since their diagnosis. The issue of the different cancer tumours and how and what treatment pathways existed for each and how equitable they were came up in a couple of conversations.

Whilst speaking to people living with cancer it was clear that there were some issues raised that could be immediately fed back to the key responsible organisations for consideration and potential action. A patient log was created and a standardised email sent to relevant personnel to share the issues raised by patients that might be within the county's gift to respond to.

The issues raised that were forwarded on were as follows:

- people wanting to ensure they are as healthy and fit as they can be ahead of any cancer treatment or operations via a pre-habilitation service
- raising awareness of the criteria and eligibility for people to access non-emergency patient transport if they have a diagnosis of cancer or who may not have their own transport to attend hospital appointments
- district nursing teams being trained and where feasible and appropriate being able to remove drains so as to reduce unnecessary travel back to the hospital for the patient
- Blood tests for cancer patients receiving treatment being prioritised within local GP practices so as to reduce unnecessary travel back to the hospital for the patient

**CANCER
YOUR JOURNEYS**

As part of the 'Improving the Cancer Journey in Powys' programme, we asked people living with cancer to get in touch and share their experiences with us. We also wanted to know what local support or services would help. These are some of the things we heard.

The hospital staff are all brilliant but then you come home and can feel quite isolated and alone.

As a carer I felt invisible and excluded from conversations. This isn't helpful.

“Your cancer journey is equivalent to being on a rollercoaster.”

Having someone who understands what you are going through (a cancer buddy) would have been really helpful.

People ask me why I'm so joyful and I say because I'm here. I'm alive.

Visit our webpage
<https://www.powysrpb.org/icjpowys>
e: ICJPowys@powys.gov.uk

GIG NHS Powys Health Board
Powys Health Board
Powys Teaching Health Board

Powys

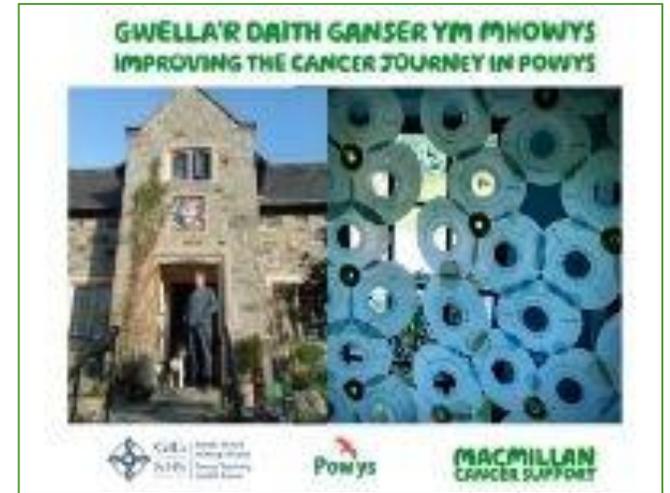
MACMILLAN
CANCER SUPPORT

RAISING AWARENESS OF THE ICJ PROGRAMME

A detailed Communications and Engagement Strategy and Action Plan was developed so as to raise awareness of the programme using a mix of channels and communication assets. An overview of some of this work follows.

- *THE PROGRAMME RELAUNCH – 21 SEPTEMBER 2020*

The re-launch of the programme saw around 30+ people come together to listen to the keynote speakers explain more about the programme. Richard Pugh delivered a powerful speech highlighting that although the nation was talking about being in lockdown that cancer could not be “furloughed” and that work in pursuit of improving Powys resident’s cancer journeys would continue.



Cllr Myfanwy Alexander, Cabinet Member for Adults Services within Powys County Council spoke about most people knowing someone with cancer and how in a rural county like Powys community played a key role in supporting individuals with a diagnosis.

Dr Jeremy Tuck gave an update on the team’s progress to date in seeking patient stories and working with partners to understand how cancer services in the county were working currently so as to inform how they could work better in the future through the launch of some pilot projects.

These presentations were then followed by the personal stories of three individuals – two of who are living with cancer and one who had cared for her husband who’d had terminal cancer. All three speakers have subsequently joined the ICJ Stakeholder group called the Journeying Together Forum which meets bi-monthly.

THE IMPROVING THE CANCER JOURNEY IN POWYS JOURNEYING TOGETHER FORUM

In the same week as the relaunch of the programme, a small group of people living with cancer came together via Teams to share their insights to begin to help the programme consider how best to engage and communicate the key messages about the programme to others. The forum has met on four occasions and have given their views on a number of things from draft social media posts to trying out the electronic Holistic Needs Assessment tool that will form the basis of the pilots. The forum signed off the content of the ICJ webpage which is hosted on the Powys Regional Partnership Board website and will also be writing some book

reviews following a successful bid by the ICJ team in collaboration with the Powys Library Service to purchase four sets of 50 books recommended by Macmillan which will be available for loan from the branch libraries in due course.

- **PUBLICITY AND PR**

Several social media posts including some with video's by GPs talking about holistic needs assessments and people living with cancer sharing their stories were developed and issued during the year.

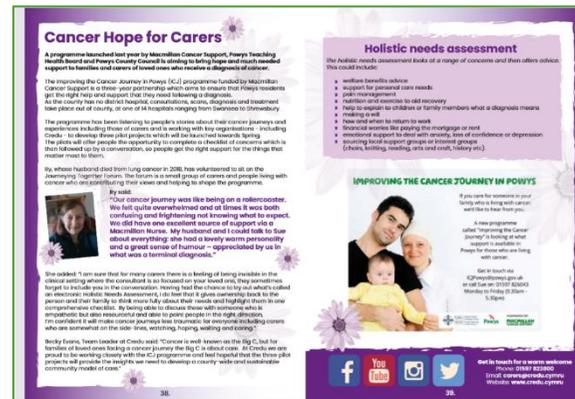
Opportunities to utilise existing partner channels to communicate with other stakeholders saw copy in partner organisations newsletters or websites including PAVO, Credu, a GP newsletter, the Wales Cancer Network bulletin and Macmillan channels. An advert was placed in the County Times (right) inviting people living with cancer to get in touch and share their stories and four press releases were issued during the year.

There have also been opportunities to work on shared social media posts with Care & Repair and a noticeboard display put in the Llandrindod Branch of Tesco for two months.

Finally, a webpage was developed and is hosted on the Powys Regional Partnerships Board website. <https://www.powysrpb.org/icipowys>



Tesco Noticeboard, Llandrindod Wells



A double page spread in Credu's Carers Chat magazine



The ICJ webpage which sits on the Powys Regional Partnership Board's website

FOCUS FOR 2021

As the second wave of COVID recedes and the vaccination programme continues at pace, many areas of health and social care delivery are looking at how to regenerate service capacity and delivery whilst recognising the risk of a third wave and the impact this may have.

In 2021, the programme seeks to build on the achievements to date. The newly appointment ICJ Programme Lead will continue to ensure programme governance remains relevant and fit for purpose to support and enable delivery planning. The appointment of an external supplier to facilitate the Theory of Change for Powys offers another opportunity for stakeholders and people who are living with cancer to shape the programme's overall objectives, the activities that will enable these objectives to be met and to help ensure the anticipated benefits are realised. Within this development of the Theory of Change for the ICJ in Powys, the rationale for actions will be clarified and measures of success will be agreed. This will form the basis of the procurement documentation that will be developed in 2021 for the appointment of an external evaluator in 2022 who will go on to work with the programme and the pilots to develop the evidence base for the preferred model.

Taking immediate action to improve the cancer journey wherever possible and appropriate, is a key value that will be further entrenched in programme delivery in 2021. Where people who are living with or affected by cancer have agreed for us to do so, their stories are discussed with a range of professionals at both our Strategic and Operational Programme Boards. Themes are considered and any feedback identified will continue to be shared with other services so that they are able to reflect and act upon this information. This feedback is maintained in a log and regularly reviewed at monthly and bi-monthly meetings as one of the ways the programme is seeking to evidence its impact.

In addition to the development of the theory of change and providing feedback to services in real time, people living with cancer, PTHB, PCC services, and Third Sector services will continue to be engaged throughout 2021, with a particular focus on areas that could not be completed in 2020.

The evolution of the pilots will continue in 2021, with each organisation embedding the foundation stage of being able to offer eHNAs to people living with cancer and establishing a community of practice so that the professionals at the coal face of offering eHNAs and developing care plans are able to come together, share learning, generate ideas, and develop solutions to any difficulties which may arise. The intention is to further explore in 2021 and implement information sharing agreements between organisations so that the objective of testing an integrated, seamless model of care can go on to be realised during 2022's evaluation.

With cancer being a top four priority in Powys, a number of partners who are able to influence this agenda regularly come together under the umbrella of a quarterly Cancer Partnership Group. The ICJ will continue to feed into this throughout 2021, ensuring the programme is integrated into the wider context and ensuring any interdependencies can be identified and managed. Of key interest to the ICJ is the PTHB's medical directorate's plans to further understand the medical model and the ICJ is looking forward to receiving the updates and information on this via the Cancer Partnership Group.