



**What matters to Wales' cancer patients?
A Cancer Services Action Plan for the Future**

A Report on Engagement Activities by the Wales Cancer Alliance

Why this report?

Following representations from the Wales Cancer Alliance (WCA) earlier in the year, the Minister for Health and Social Services agreed that the draft Wales Cancer Services Action Plan (the plan) needed additional third sector and patient engagement prior to publication. Publication of the plan is due to take place towards the end of January/early February 2023, offering a short window of opportunity to the WCA to plan, produce, deliver and report on patient engagement activities.

The WCA believes that a piece of work as important and as consequential as the plan - its strategic, collaborative nature and covering a 5 year time span - needed a public consultation and much more patient engagement than was achieved over the month available to us.

We chose to make the most of this opportunity to engage, but have been constrained by time, limiting what we have been able to achieve. The third sector and patient engagement needs to be built into future iterations, reviews and evaluations of plans of this nature to better reflect those needs. The WCA exists to support activity of this nature.

This report compliments earlier engagement activities in October 2022. Those two online sessions were facilitated by Cancer Research UK, though they took place without the benefit of any draft plan. The sessions focused on what people would like to see in any draft plan, and the Wales Cancer Network (WCN) received a report of that activity in November 2022.

What we did

Survey

Over the course of several days, between late November and early December 2022 a short Google forms survey was produced by a small task and finish group representative of the overall WCA membership.

The survey questions reflect a patient's cancer journey, milestones along the cancer pathway. The survey was distributed amongst the WCA membership and publicised on social media, by the WCN and amongst forums and stakeholder networks across Wales (Appendix 1).

The survey also captured a person's cancer type and health board. The survey was open for responses between the 6th and 19th December 2022.

Stakeholder focus groups

Developed alongside the survey, three stakeholder events were planned, produced and delivered during December 2022, ahead of the Christmas break.

Held in person, small focus-group events allowed representatives from the WCA and WCN to discuss the plan - and in particular, the 'improving the patient experience' section of the plan - with people with a cancer experience.

The Maggie's centres in Cardiff and Swansea kindly offered to host the two south Wales events, while a third event was organised to take place relatively close to Ysbyty Glan Clwyd, at the Optic Centre, St Asaph Business Park.

Wales Cancer Alliance representatives facilitated all three events, while WCN representatives attended the Cardiff and Swansea focus groups as observers and to answer any questions raised around the development of the Plan from an NHS perspective.

In total 16 people attended the three events:

5 in Cardiff, 16th December

5 in St Asaph, 19th December

6 in Swansea, 19th December

The events were 2 hours long, refreshments were provided, and attendees were able to claim their travel expenses back from the WCA.

Notes captured the main talking points of the conversation

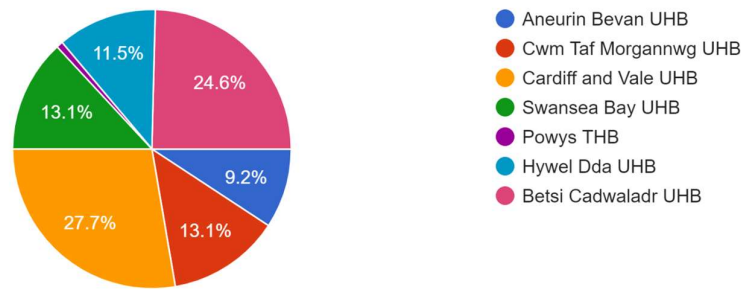
What matters to people with cancer?

The Survey

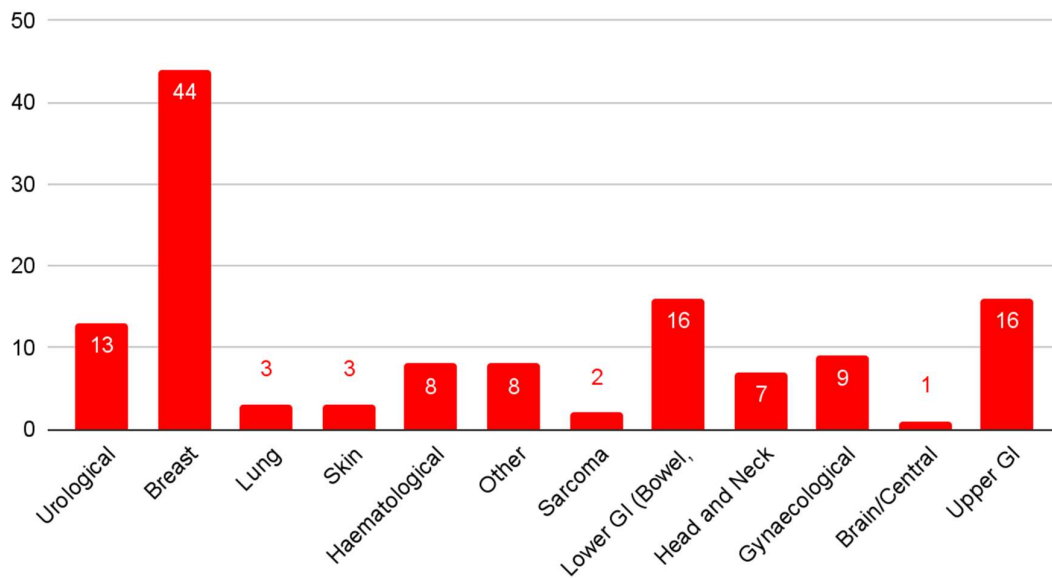
Over the course of a fortnight 130 people responded to the survey. It reflects the direct cancer experience of the overwhelming majority of respondents, though in a small number of cases people responded on behalf of a family member or friend.

Which health board area do you live in?

130 responses



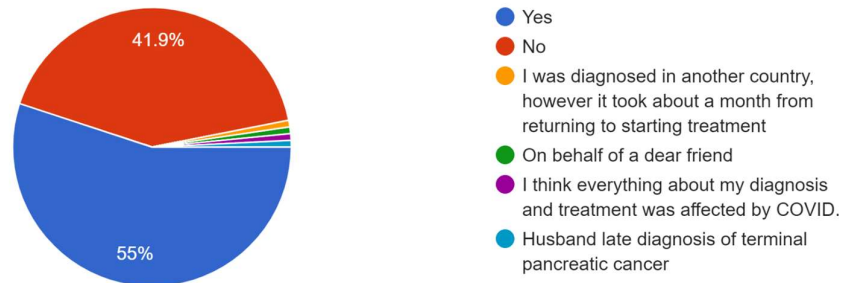
Which type of cancer do you have, or have you had in the past? (130 responses)



Your Diagnosis

Could the way you were diagnosed with cancer have been improved? (i.e. from the point you were referred for more tests, to when you had your operation or started your treatment)

129 responses



Just over half of the respondents (55%) believed that the way their cancer was diagnosed could have been improved while 41.9% seemed satisfied with the experience of their diagnosis.

“Could the way you were diagnosed with cancer have been improved? (i.e. from the point you were referred for more tests, to when you had your operation or started your treatment) if so, how?”

75 out of 127 responded to this question. The responses to this were dominated by stories of delayed diagnosis with nearly half of all responses referring to delays. Some of these were directly attributed to COVID. Many responses (15) focused on the ways in which information was (or wasn't) communicated, with some saying there wasn't enough information, and others reporting that they didn't feel listened to or that they weren't treated compassionately.

13 patients explicitly referred to delays experienced during primary care, referring to a lack of knowledge or not being taken seriously by their GPs, or delays in referrals, though it likely that many for whom this was not explicit also experienced delays at this stage.

For two of the respondents, their late diagnosis was a result of not being listened to because of their age. Whilst cancer in younger people is less common, it should not be discounted for those presenting with symptoms outside the higher risk age brackets:

Due to my young age my cancer was found late, more education needed for health care professionals that cancer can happen at any age. Not to rely on CEA levels as this is not a reliable marker for all patients. Easier access to a colonoscopy which took me over 18 months to access via my dermatologist. I was constantly told my ongoing symptoms are not anything serious due to my age this approach nearly cost me my life.

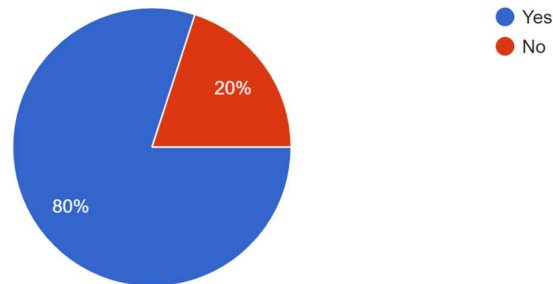
Twelve of the respondents spoke of having to be proactive in their treatment, either through pushing for tests or by opting to go private.

A summary of the frequency of responses can be found in the table below.

Theme	Sub-theme		No.
<i>Medical</i>	<i>Diagnosis</i>	<i>Delayed (32)</i>	34
		<i>Misdiagnosed (2)</i>	
	<i>Delay at primary care/lack of GP knowledge</i>		13
	<i>Relating to scans/tests</i>		8
	<i>Proactive patients</i>	<i>Used private Option (6)</i>	12
		<i>Being own advocate (6)</i>	
	<i>Scans/test</i>		8
	<i>Waiting to start treatment</i>		4
	<i>Covid</i>		4
	<i>Treatment</i>		2
	<i>Other primary care feedback</i>		1
	<i>Lack of efficiency</i>		1
	<i>Person centred</i>	<i>Poor communication/lack of info</i>	
<i>Patient needs/mental health</i>		5	
<i>Going through it alone</i>		1	
<i>Other</i>	<i>Systemic problems</i>		4
	<i>To much travel</i>		2
	<i>Unclear</i>		1

When cancer is caught early, it is easier to treat. Do you think a national target should be set for the number of people diagnosed with cancer at an early stage?

130 responses



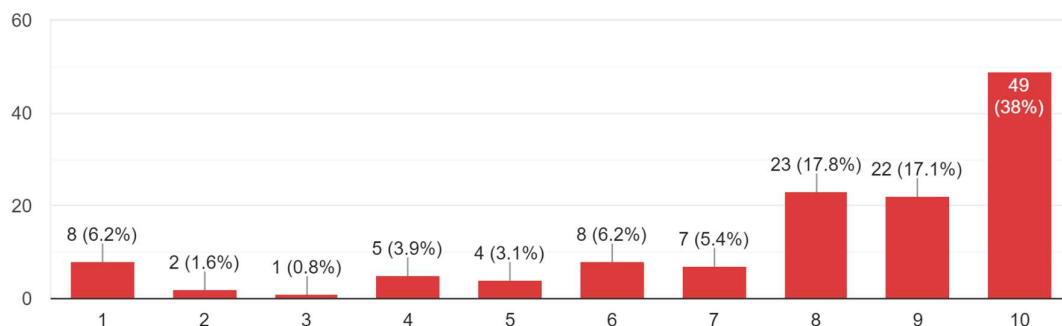
A significant majority of respondents (80%), presumably including people satisfied with their diagnostic experience, believe there should be a national target for the number of people diagnosed with cancer *at an early stage*. The question was left open to interpretation.

People may have interpreted “early stage” in terms of speed and in the context of their overall cancer experience, or in terms of cancer staging. From conversations with people with a cancer experience in the focus groups it seems more likely to be the former than the latter - people are more likely to associate improved outcomes with faster diagnosis. Both the survey and focus group responses suggest clear support for actions aimed at improving earlier diagnosis, including specific targets. Additional work, including patient engagement, should be undertaken to explore this further.

Your Treatment and Support

After your diagnosis, how well were your treatment options explained?

129 responses

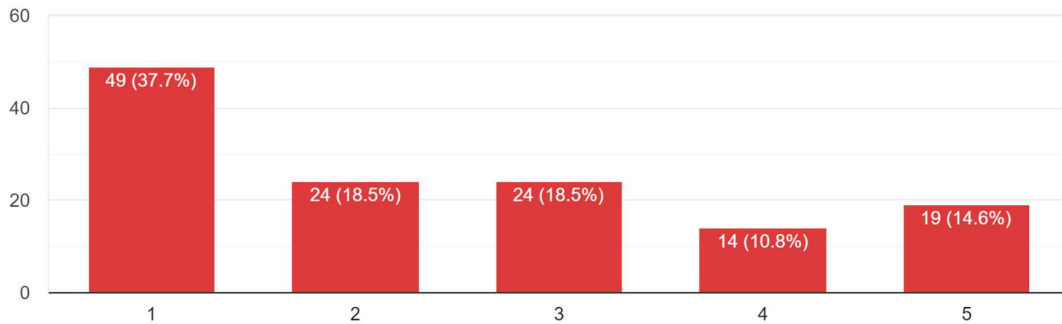


A large majority (84.5%) of those who responded held a positive view concerning the explanation of their treatment options following their cancer diagnosis - point 6 on the scale and above. 38% of respondents felt that their treatment options were explained

exceptionally well. However, 12.5% of respondents, over 1 in 10 patients held a less positive view, with over 1 in 20 (6.2%) rating their experience as *not very well*, the lowest point on the scale.

How content were you with the amount of information you were given to help you make choices about your treatment and care?

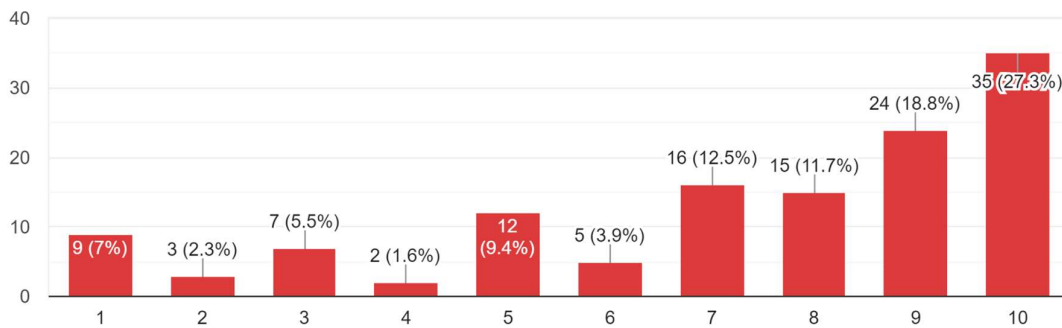
130 responses



The scale inverted, 1 equalling content, and 5 not content, nearly three-quarters (74.7%) of respondents ranked themselves content or were neutral on the matter. Slightly over a quarter of respondents were less than content concerning the amount of information they were given to help make choices concerning their treatment and care.

How well do you feel were you supported through diagnosis and treatment for your cancer?

128 responses



74.2% of respondents felt that they were supported through their diagnosis and treatment for their cancer. 9.4% gave a neutral response, and a concerning 16.4% gave a negative response.

“Thinking about your cancer diagnosis and treatment, what went well?”

119 out of 130 patients responded to this question, and whilst seven of these did not report anything positive, most had positive feedback about at least one area of their care:

Everyone from my GP first sending me for tests and right through the chain of events of admission, operation and after care, I was treated attentively, all the staff were so kind and understanding. I felt privileged to be looked after so well. A real credit to our cherished NHS.

The overall feeling in this response is that once diagnosis has been made, treatment was largely well-received and managed, and in a timely manner for those who mentioned the timeframes (25). Again, there's a strong emphasis on communication as key to positive experiences. Staff are celebrated here for instances of kindness, compassion, and taking the time to explain things well.

Every contact with healthcare staff was great - ie they explained things well, they answered all my questions, they followed my lead in respect of tone/information required/emotional support needed etc.

Some respondents had mixed experiences – with staff in some areas giving a higher standard of information and/or support than others.

I feel that my consultant listens to me and will adapt treatment around me to give me the best quality of life. But other than her and if I'm lucky enough to see her I don't get any other support from breast care nurses.

Theme	Sub-theme		No.
Medical	Treatment		41
	Staff	General	20
		Specialists	7
		Nurses	2
	Speed of service		25
	Diagnosis		11
	Primary care feedback		4

	Velindre/Maggies	4
	private healthcare	2
	Remission/LWC	26
Person centred	Communication	24
	Patient needs/mental health	6
Practical/ Other	Negative feedback	8
	General	5
	Systemic Comments	2
	Distance to treatment	Negative (1) Positive (2)

“Thinking about your cancer diagnosis and treatment, what could have gone better?”

119 out of 130 people responded to this question. Because this covers both diagnosis and treatment, there were some themes emerging in this response set, with some duplication with the first free-text response. Again, waiting for a diagnosis was noted by many respondents, and the impact of this on patients:

The time to get scan results is stressful. It can be hard to know where to start looking for information - you don't know what you don't know - and it can feel overwhelming.

The most prominent theme in this response set was around the communication and information received by patients, particularly relating to side effects and aftercare more generally.

A breast surgeon who was empathic, not inept and insensitive. Her words continue to ring in my ears nearly 4 years later. Support initially, none provided by Breast Test Wales after the day of diagnosis. Having questions answered. Being given decent written or on-line information or signposting to

it. It is devastating to discover information such as the NICE guidelines when it is too late and they have clearly not been followed.

Again, the frequency of responses is summarised below.

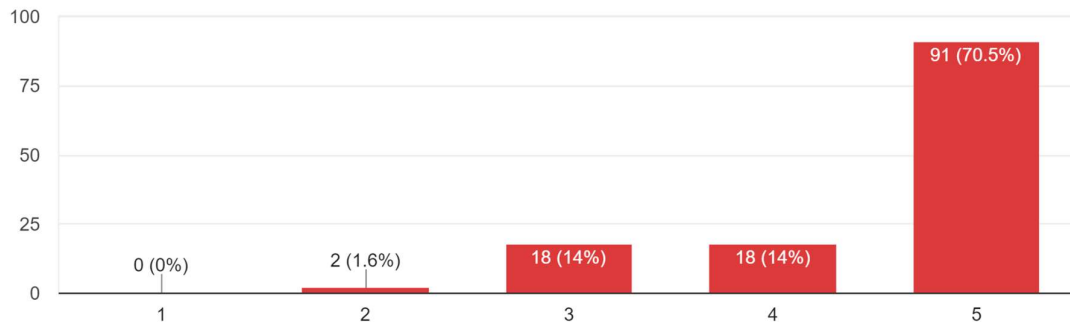
Theme	Sub-theme		No.
Patient centred	Poor communication/lack of info	Information about outcomes/side effects/aftercare (14)	46
		Being informed/communicated with (13)	
		Manner of communication (9)	
		Overload/overwhelmed (5)	
		Timeliness of information (2)	
		Questions answered (2)	
		More discussion (1)	
	Aftercare/side-effects		12
	Patient needs/mental health		7
	Holistic/general support needs		7
	Not enough time to think		2
Not being listened to/being own advocate		2	
Going through it alone		1	
Medical	Aftercare/side effects		18
	Delayed diagnosis		17
	Treatment/options		8

	Waiting to start treatment	7
	Staff	4
	Scans/tests	3
	Primary care feedback	3
	Lack of specialist support/treatment in area	2
	Lack of knowledge	2
	Reconstruction	1
	Access to trials	1
	Secondary cancer	1
Practical/ Other	Systemic/administrative problems	16
	Site/ward specific issues	8
	Transport/travel	8
	Unclear/general	6
	Positive feedback	6
	Covid	4

Clinical Trials

How important do you feel is it for people affected by cancer to be offered the chance to take part in clinical trials?

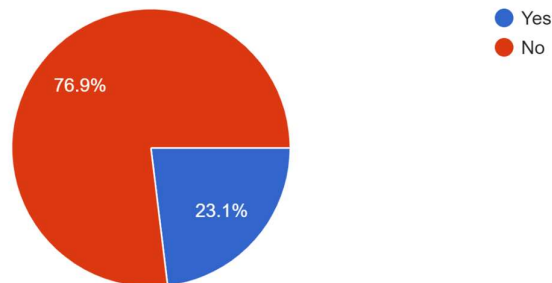
129 responses



All but 2 respondents had a neutral view or held a positive view on the importance of being offered the chance to take part in clinical trials.

Were you offered information about taking part in a clinical trial?

130 responses



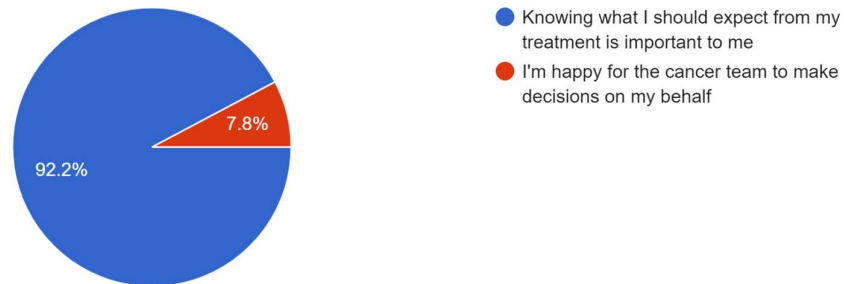
However, 76.9% of respondents could not recall being offered information about taking part in clinical trials. 23.1% of respondents did receive information.

Attention needs to be given to increasing the number of clinical trials available to cancer patients in Wales, it is welcomed by patients. But the information patients receive about these opportunities must follow at an appropriate stage of their cancer journey.

Co-produced Care

Is knowing what you should expect from your treatment important to you, or are you happy for your cancer team to make the decisions on your behalf?

129 responses



92.2% of respondents wanted to know what to expect from their treatment, and therefore be involved in decision-making, rather than delegating decisions to their cancer team to make decisions on their behalf (7.8%).

The vast majority of cancer patients want to be involved in their treatment and care, whereas a small percentage of people are happy for the cancer team to make decisions on their behalf. It is vital that people living with a cancer diagnosis are supported to be as involved in their care and treatment as they would like to be, and for healthcare professionals to recognise that a person's involvement may fluctuate and, as such, a person's preferred level of inclusion should be subject to regular and ongoing review.

“Is knowing what you should expect from your treatment important to you, or are you happy for your cancer team to make the decisions on your behalf? Why is this?”

122 out of 130 people responded to this. As expected from the response to the question “Is knowing what you should expect from your treatment important to you, or are you happy for your cancer team to make the decisions on your behalf?”, a significant majority of respondents used the ‘why is this’ field to explain exactly why knowing what to expect is so important to them, with one respondent saying:

Every patient should have a voice in their treatment plan

However, not all patients *want* such detailed information. Several reported feeling overwhelmed (here and in other questions), and one suggested a more personalised approach would be valuable:

I think it would very useful if you were asked at your first consultation what level of detail you would like to receive during future appointments so that the relevant information / data is made readily available as needed.

Being well-informed helped patients feel more in control at a time when so much was beyond their control, and that knowing more helped them manage their illness more effectively

I found I could be prepared for what could happen & what I could do to give my treatment the best chance to work.

I feel I need to be in control of my treatment, and make decisions myself, based on the advice of professionals. So far I have followed all advice and accepted the recommended treatment plans. However, I have heard that those people that are more pushy have a better survival rate. Therefore, I will want to ensure that my treatment plan gives me the absolute best chances of avoiding recurrence.

Although more than half of respondents said they were content with the *amount* of information they received, it's worth bearing in mind the points made around how information is delivered – both in terms of empathy and the types of communication. 18 said that having better information helped them to make joint decisions and/or improved their relationship with their cancer team.

Theme	Sub-theme	Referring to:	No.
Person centred	Being prepared/informed		81
	Control		11
	My body		10
	Patient well-being/mental health		7
	Poor communication/lack of info or options		6
	Overload		1
Medical	Making own decisions		33
	Relationship with cancer team/joint decision making		18
	Decision made by others		11

	Treatment	8
	Aftercare/side effects	5
	Choosing when to stop	2

“Do you have any other comments about anything relating to your cancer diagnosis, treatment or care?”

89 out of 130 responded to this question, and many used the opportunity to reiterate points that had already been made around speed of diagnosis, and their needs for greater information and aftercare, around, for example, mental health.

I have no complaints about the cancer diagnosis or treatment. After care could have been better. I did not require any further medical treatment following surgery and subsequent complications, but could have done with mental health support, or at least for it to be more explicitly signposted.

Theme	Sub-theme	Referring to:	No.
Person centred	Information	Better informed (11)	17
		Lack of choice (4)	
		More contact (2)	
	Patient well-being/mental health	17	
	Aftercare/side effects	7	
	Metastatic/Secondary/LWC	5	
	Holistic support needs	4	
	Education/Awareness	2	
	Age related feedback	2	
Carers	1		
Practical	Regional/site specific issues	13	
	General feedback/advice	8	
	Travel	3	
Medical	Diagnosis	9	

	Staff	Good	8
		Bad	5
		Specialist/key worker	5
		Primary care	4
		Communication between teams	2
	Treatment/delays		5
	Tech improvements		2
	Screening		2
	Access to trials		1
	Palliative care		1
	Genetics		1
Other	General/positive feedback		18
	Survey feedback		3
	Historic		2

Focus Groups

Maggie's Cardiff, 16th December 2022

Development & Implementation of a Cancer Action Plan

The detailed, technical nature of the plan was acknowledged, beyond the expertise and competence of many present. Focus group attendees were informed that the WCN are developing a 5-page "easy read" version that they would like to run past participants.

Important that patients' needs are at the front of politician's and clinician's minds.

"Get beyond competitive and cultural barriers."

Plan needs deliverables, milestones and accountability. Would like to see what NHS Health Boards and Trusts are going to do with regards to cancer services and report against the relevant parts of the plan.

Going to be a long battle implementing the plan, Wales is a long way from achieving its ambitions.

Co-Production of Care

Concerns that advances in cancer are not filtering down into primary care. Feelings that cancer is not in the mind of the GPs from an early stage; inconsistency in GPs sending patients straight to test.

Role for 3rd sector to engage with GPs - but NHS need to be an active participant.

Concerns expressed about a workforce becoming more dispassionate, overlooking the person being cared for. Example provided of experience of one person during treatment during the pandemic, left a lasting impression and negative experience.

Assessing and Meeting People's Needs & Signposting to Emotional Support

No-one explained who could offer support in the third sector. No information provided. Need to steer people to good, safe and updated information.

Lack of information at end of treatment, during the pandemic.

People's preference is mixed, some want physical information in a folder (or somewhere else to keep it all in one place), others prefer their information

electronically via email. Be prepared and able to personalise according to preference.

While it has its limitations, the information now available is better than in the past, patients then were much more passive and deferred to their clinicians.
Role for the third sector to get the right information to the individual and their needs.

Need for a “key worker”/ “support worker”. Any attempt to re-write or re-work the role as set out in current guidance would be welcome.

For holistic needs to be met local authorities need to be involved too.

Nothing in plan sections concerning people with disabilities, holistic needs of cancer patients beyond their diagnosis that may impact on their wider well-being.

A key worker needs to be a co-ordinator - someone who can identify needs and issues and help with getting the support in place. Their “specialisms” and skills would concern information and support coordination.

Question concerning where the “key worker” would sit in the system, especially if care and treatment between a person’s health board and a cancer centre sitting in a separate trust. Key worker could be responsible for ensuring care is joined up and accountable - responsible for the person from diagnosis through to beyond treatment and social care support.

Role for the key worker to help capture PREMs through surveys.

Digital technology provides important tools for the roll out of PREMs. Still feels like the NHS are behind many other services concerning the use of digital technology - the great big paper file still in use across hospitals. Need for simplification and standardisation.

OpTic Centre, St. Asaph, 19th December 2022

Co-production of Care

Links with primary care are terrible. GPs are the last to know and therefore often not in a position to support.

Systems do not speak to one another.

Prescribing issues arise, especially for medical devices. Panic that they won’t arrive in time and trying to make the prescription from secondary care work in the community is really challenging.

Capturing patient experience is important, but this is challenging as everyone has different expectations. Being offered CHOICE is the most important thing and this is what should be measured – that you are able to make informed choices based on timely information. Knowledge is power when it comes to making choices. Younger patients want to feel empowered. Gone are the days when you do as your dr tells you.

Suggestion:

“Ask people to complete surveys when they are waiting in outpatients for follow up appointments. You need different surveys at different points in the system.”

Assessing and Meeting People’s Needs

Needs assessments should happen at the beginning of treatment, but then should take place again during the treatment pathway when needs change. “You don’t know what you need until your treatment starts and how bad it is going to be”.

Carers also need their needs assessed. If it wasn’t for carers, then people would have issues getting to and from their appointments for radio / chemotherapy / follow ups. Real issue for people with drains, new stomas etc.

Carers are also expected to deal with personal care which can cause issues within a marriage when you stop becoming a lover and turn into a carer.

Blue Badges are important.

There is a need for designated parking for people who are attending hospital for treatment. This causes anxiety and panic.

Signposting to Emotional Support

Survivorship and support for survivorship is vital. Sense of being sent out to the world on your own when treatment finishes e.g. Lymphedema – didn’t have a clue what was normal or not.

There is a lot of mixed emotions, anger, frustration, relationship issues.

People don’t realise they will need support and some may not need any! Very personal and complex.

You must be informed so you are in a position to receive information, process what is happening and to be able to make decisions.

It is important that people are made aware that the emotions they are going through are normal.

Peer support is incredibly important.

Bravery is something that all will have to draw upon.

Palliative care pathways are vital and more needs to be done to normalise this approach so you can live well with incurable cancer.

Maggie's Swansea, 19th December 2022

Development & Implementation of a Cancer Action Plan

Any plan comes with a glossary and be very aware of using abbreviations and acronyms.

Co-production of Care

Some people are on more than one pathway (have multiple cancers) - so don't just fit 'in one box' - when asked for information on your experience the survey's mean 'please can you answer about one of your cancers' but as the patient 'you want to answer about both (all) of them'.

When you have secondary breast cancer - there is no '*end of treatment*'.

How do patients get to see what actual 'changes or improvements are made to the system'?

Could there be a rolling/open survey that you can fill in at anytime? One participant said:

'your experience doesn't finish when your treatment finishes'.

Sharing of information between Health Board (or lack of) seriously affects your experience.

Can patients carry their own records? - (PKB and other examples were given) but overwhelmingly the group thought better access to your own information and better sharing between teams and HB's would assist the ability to co-produce care (one participant talked about having 4 patients numbers - within one Health Board) so there's an explicit understanding about how 'rubbish' the information system can be!

It was acknowledged that the X-Ray system around Wales - talks to all Health Boards - so why can't the other systems?

'the more 'bolshy' you are, the better your care'.

The GP was excellent - really took care of me - called me out of hours etc,

None of the 6 participants had been asked to complete a survey at any point.

Solid tumour cancers and haematology cancers are treated very differently.

One participant felt that the NHS was a *"if it moves measure it"* environment and asked that if we collect data from people and they take up their time to do it that we MUST use the data and let people know what we are going to do with it.

Resources came up a lot- one participant said *"we can develop wonderful plans but where are the resources to deliver on them"* discussions followed around working differently.

Discussed needing better links between primary and secondary care, and even between primary care/ community services e.g. GP and pharmacy.

Assessing and Meeting People's Needs

One participant discussed having a fantastic GP who told him he had cancer, but who has also provided a lot of support and signposting to different services for him- he got the majority of support from this GP even though he had a CNS in secondary care/ contact number for them he didn't really use for support.

Travel stresses - west Wales needs more investment to reduce the amount of travel people have to do.

Teenage Cancer Trust in Cardiff are amazing - but some people can't afford the travel to get there (there didn't seem to be any understanding that travel costs could be claimed back).

Getting the right drugs at the right time can be very stressful - talk of people driving around Swansea trying to find a pharmacist with the right drugs.

There is a key worker on the Teenage and Young Adult ward at Cardiff - but they are not available to young people other than in an 'inpatient capacity'.

The Clic Sargent social worker was linked to Maggie's Swansea - which was very helpful - but then the post disappeared.

No-one mentioned or explained about the mask fitting in radiotherapy - it was like being 'waterboarded'.

"My Macmillan Head and Neck nurses were brilliant - as was Maggie's."

The Head and Neck team in Swansea didn't mention Maggie's and Maggie's is not advertised in the Radiotherapy department - very frustrating for patients and family members.

The definition 'care plan' can be quite confusing - does it mean what treatment you may get or your holistic needs?

Signposting to Emotional Support

Maggie's took care of emotional needs.

"I had to find Maggie's myself - my clinical team didn't mention that I could get emotional support from Maggie's or anywhere."

"It's so obvious that my CNS was so busy - I didn't want to ask her about where I could get support."

Clear that the doctors are very busy and stretched beyond capacity - people mentioned having long conversations with nurses and doctors out of hours, because there is no time for them to call or speak to you during working hours.

"First impressions matter" – patients pick up on how busy teams are. Asked whether a "navigator role" would be appreciated, patients reported that although teams were busy they felt that they would have been there for them if they needed them.

Once treatment is complete the hospitals wave goodbye to you, but that is when 'mental/emotional' support is required. People talked of needing significant support once treatment had finished.

One participant asked *'where do family members go for support?'* This lady was originally from Poland and spoke of the dynamic between family members - in her experience/culture the family members are 'angry' that the person with cancer had caused so much distress to the family. She was visibly upset by the experience of managing this family dynamic.

Generally, nurses are not promoting Maggie's or other support organisations sufficiently enough.

One participant suggested that Student Nurses could be used more to promote cancer charities and support organisations to patients and family members.

Participants discussed that there are lots of charities out there offering support and it can sometimes be difficult to know who, and where to go to for what and at what time. One of them mentioned that *"you don't know what you need until you need it"*.

Discussion around upskilling generalist health care staff that are working in areas outside of cancer so that they are informed about where they should be seeking help and support- particularly in emergencies or out of hours.

Conclusions

What matters to people with cancer?

We have been able to identify several strong overall themes from this piece of work, that we want the WCN to reflect upon in the production, and implementation of the plan.

Early, faster diagnosis.

Many contributors experienced delays to the diagnosis of their cancer. Many were also aware of the need for a diagnosis to happen sooner, rather than later. As a result, some stepped outside of the NHS and paid privately for their tests and diagnosis, some insisted their GPs took their concerns seriously before being sent for tests. For anyone facing delays, in some cases up to and over 20 weeks, this period was one of struggle that they would not want others to experience.

Information between the point of suspicion and diagnosis.

From the feedback we have received, and despite the fact that a person's cancer journey is officially measured from the point of suspicion, the quality and quantity of information and support available to people at this earliest of intervals is limited. Support from many cancer charities may not have been triggered prior to diagnosis, leading to increased pressure on primary care to find and provide information.

Consistent, compassionate treatment and support.

While the overall majority of people received positive treatment, care and support experiences, the opposite has been the case for sizable minorities, which is concerning. People generally reported positive feelings toward the medical treatment they received. However, anecdotal evidence from the pandemic onwards suggests that the medical safety protocols, distance requirements and overall workforce pressures may have created barriers to communicating compassionately to some people with cancer.

Where people felt that their treatment and support could have been delivered better, information was flagged as a significant issue for improvement - whether concerning the treatments and possible side effects, or the way in which the information was communicated.

Being an active participant in their care and treatment.

A small minority of people want decisions concerning their treatment and care to be taken on their behalf by their medical team, the overwhelming majority of people (92.2%) want to better understand what is behind those decisions, and by extension, participate in their care and treatment. Being better informed helps people manage their situation and feel empowered at a time when feelings of powerlessness might overwhelm a person.

Participation also involves a degree of personalisation that comes from understanding the needs of the person with cancer that would improve the relationship with the medical team responsible for treatment and care.

Having their holistic needs assessed and supported.

Related to the preceding section, this came up repeatedly in the conversations with people with cancer at the focus group events.

People were largely agnostic concerning the name of the role - whether a “key worker”, a coordinator or a navigator. People want a single named person, a single point of contact, who can assess a person’s holistic and changing needs throughout a cancer journey, and signpost onto support, whether in the NHS, third sector or local authority social care. That person might also be able to advocate on behalf of someone with cancer in more difficult circumstances.

Information about clinical trials.

Clinical trials matter to people with cancer, yet too many people fail to receive information concerning their availability and accessibility. Further work needs to be done to increase the numbers of people receiving appropriate, relevant information.

From the levels of interest and engagement the WCA has managed to generate and capture over a short period of time, it is clear that people with cancer want to contribute to the development of cancer policy in Wales. While time was a significant constraint - we are unable to describe what took place as a consultation - we have managed to survey 130 people with a cancer experience, and speak to a further 16 people with cancer in three focus groups across the country.

The engagement process of the past month has its limitations, that we acknowledge. The deadline set for production of this report by the WCN dictated the timeline of activity. The survey was produced at pace to maximise the time available to WCA members to circulate to their networks and for people to respond. Children and young people; people with secondary cancer and people at the end of life may have struggled to respond to sections of the survey in a meaningful way.

The use of WCA member networks and forums in Wales may have also meant that the survey results do not reflect some tumour sites particularly well, for example only three people diagnosed with lung cancer completed the survey. We are confident that with more time, we would have been able to mitigate and address some of these issues.

The Wales Cancer Alliance welcomes ongoing discussions with the Wales Cancer Network about how to best utilise the expertise of the third sector in engaging with people who have been directly affected by cancer as the Cancer Services Action Plan is implemented across Health Boards and Velindre NHS Trust.



Developing a new Wales Cancer Services Action Plan

The Wales Cancer Alliance need people affected by cancer and those with experience of cancer services in Wales to help develop Wales' new NHS Cancer Services Action Plan.

A plan is being developed by the Wales Cancer Network and Welsh Government to direct and drive cancer services until 2026. The plan will cover ways to improve early diagnosis of cancer, reduce cancer waiting times and reduce variation in cancer services across Wales – it could have the potential to improve future cancer outcomes.

This is your opportunity to have your say and to help ensure plan is informed by the experiences and views of people affected by cancer in Wales.

If you are completing this survey on behalf of a loved one, please answer it as if you were responding from their perspective.

This survey will close at 5pm, 19th December 2022.

 secretary@walescanceralliance.org (not shared)
[Switch accounts](#)



*Required

Your diagnosis

Could the way you were diagnosed with cancer have been improved? (i.e. from the point you were referred for more tests, to when you had your operation or started your treatment)

Yes

No

Other: _____

If yes, how could it have been improved?

Your answer

When cancer is caught early, it is easier to treat.

Do you think a national target should be set for the number of people diagnosed with cancer at an early stage?

Yes

No

Your treatment and support

After your diagnosis, how well were your treatment options explained?

1 2 3 4 5 6 7 8 9 10

Not very well Exceptionally well

How content were you with the amount of information you were given to help you make choices about your treatment and care?

1 2 3 4 5

Very content Not content

How well do you feel were you supported through diagnosis and treatment for your cancer?

1 2 3 4 5 6 7 8 9 10

Not very well Exceptionally well

Thinking about your cancer diagnosis and treatment, what **went well**?

Your answer

Thinking about your cancer diagnosis and treatment, what **could have gone better**?

Your answer

Were you offered information about taking part in a clinical trial?

Yes

No

How important do you feel is it for people affected by cancer to be offered the chance to take part in clinical trials?

1

2

3

4

5

Not very important

Very important

Is knowing what you should expect from your treatment important to you, or are you happy for your cancer team to make the decisions on your behalf?

- Knowing what I should expect from my treatment is important to me
- I'm happy for the cancer team to make decisions on my behalf

Why is this?

Your answer

Do you have any other comments about anything relating to your cancer diagnosis, treatment or care?

Your answer

Which type of cancer do you have, or have you had in the past? *

Choose


Which health board area do you live in? *

Choose

Your date of birth

Click on and type your birthdate into the day/month/year spaces below, or use the calendar function to scroll to find your birthdate.

Date

dd/mm/yyyy 

Your name (optional)

Your answer

Submit

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