

Recovery Package Patient Survey Report September 2018

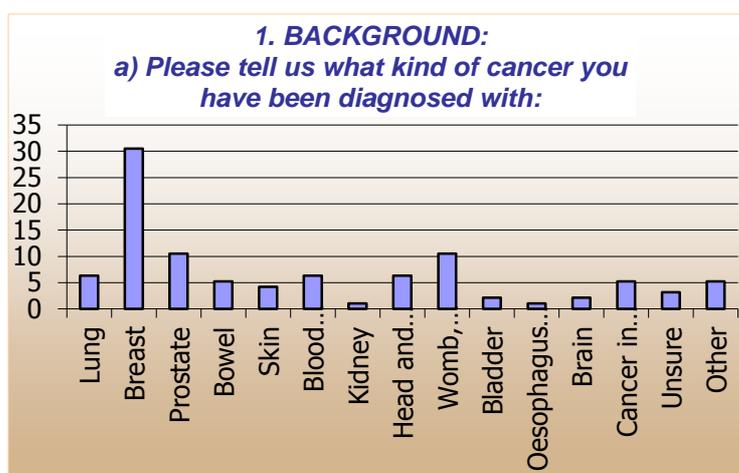
Introduction

The West Yorkshire & Harrogate Living With and Beyond Cancer Team devised a survey to ask about patient's experience and views of the different elements of the Recovery Package. The survey was reviewed by the Lead Cancer Nurses, Cancer Alliance engagement lead and a cancer patient group, before going live in July 2018. It was available online via the Cancer Alliance website and also in paper format via CNSs/Macmillan or Cancer Support Centres (where both the paper version and a flyer with the link were available). The purpose of the survey was to seek patients views in order to inform Alliance Recovery Package events – a Recovery Package Focus Group for CNSs and Cancer Care Co-ordinators on 26th July 2018, a multi-professional Recovery Package Implementation Event on 11th October 2018 and a Listen and Design CCR Event on 8th November 2018. The outputs from these events would then be used to support Trusts in West Yorkshire & Harrogate to ensure that all patients have access to the Recovery Package by 2020.

The survey asked patients whether they received the different elements of the Recovery Package including Holistic Needs Assessments, Care Plans, Treatment Summaries and Health & Wellbeing support. Each of these elements was explained in detail at appropriate points in the survey to clarify what was meant by these terms. Patients were asked to comment on the benefits of each of these if they received them and what the benefits would have been, had they received them. Patients were also given the option to engage with the Alliance on other work if they wished to do so.

Who Completed the Survey?

A total of 86 patients completed the survey, 75% of whom were women, 20% men and 5% preferred not to say. Ages of patients ranged from 40 to 76 years and all six places of West Yorkshire and Harrogate were represented, including patients receiving a diagnosis or treatment in all six acute trusts. The majority had received treatment in Leeds (37%) and Calderdale and Huddersfield (28%). 47% of the patients had been diagnosed with cancer in the last three years, with the other 53% being diagnosed from as early as 1998. In terms of tumour groups, the largest respondents were those who had a breast cancer diagnosis (31%), followed by prostate cancer and gynecological cancer (each 11%) and blood cancers (6%). The following chart indicates which cancers patients had been diagnosed with:

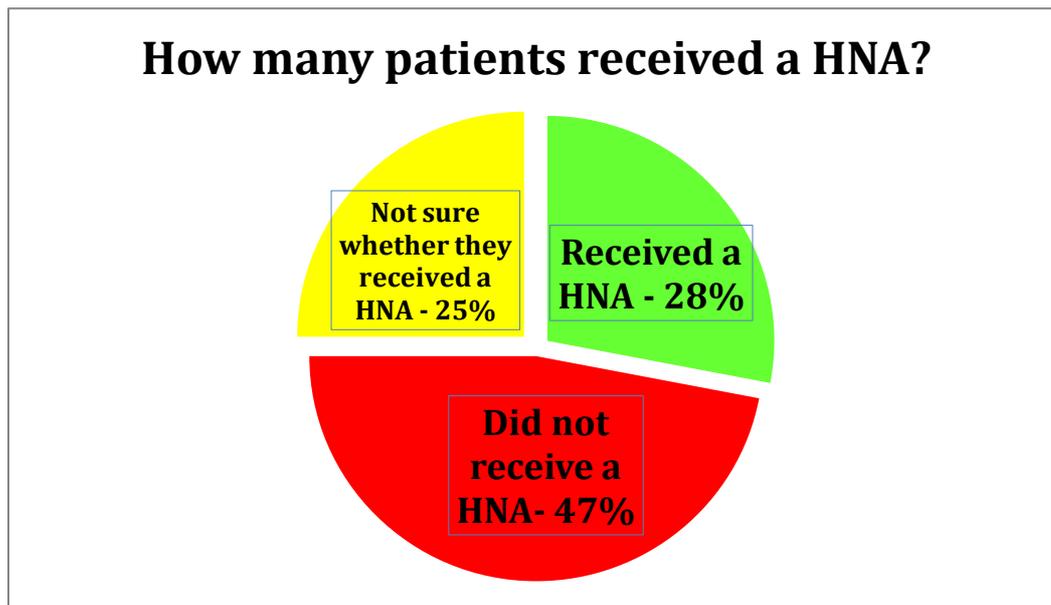


98% of the patients completing the survey were white British, with 1% African and 1% Asian

patients. This statistic shows that the survey is not representative of all ethnic groups across West Yorkshire and Harrogate and future surveys would need further engagement to seek the views of a wider group of patients. 22% of the patients considered themselves disabled – 17% had a physical disability and 5% a mental health condition.

Holistic Needs Assessments (HNAs)

Patients were asked whether they received a HNA and the benefits of this and the results are shown below. Bearing in mind that 53% of the patients who contributed to the survey were diagnosed before 2015, they are unlikely to have been offered the elements of the Recovery Package as it only started to be introduced in 2014/15. However, it was still worthwhile to ask how this could have helped and improved their experience.



Of the patients who received a HNA, only one reported that this was not helpful. Others made comments about how the HNA benefitted them and these included:

- Made me think about what I really needed. I knew that if anything changed it could be sorted out.
- The fact that I was given every opportunity to ask about anything I was unsure of and to have information clearly presented to me without feeling any pressure.
- Allowed me to be aware of the support systems and help available to me during my illness and afterwards.
- Knowing there was someone to listen if needed – reassurance and help if required.
- I was made aware that I could contact someone at any time.
- Helped to talk through problems that may arise.
- Finding out about other sources of help available.
- It was very helpful when medics took the time to find out about my lifestyle and what would need to change.

Some other comments were made about support needs:

- I had support initially from a breast care nurse but nothing after treatment completed. There was no support following discharge. Need to be able to discuss anxieties after discharge with someone plus be able to talk about any issues that may occur following discharge.
- I'm not sure if a HNA is too early after diagnosis, if it's an information overload and this kind of thing is the last thing on the patients mind.
- Very little advice and support given as to how to tell my 6yr old.

Holistic Needs Assessments (HNAs)

- It made no difference. The staff were not able to effect any actions.

Patients who did not receive a HNA were asked how this could have helped them and they reported:

- Yes - I might not have felt so alone and able to ask more about my diagnosis.
- It would help to discuss all these topics and to get help and advice from a professional instead of wondering what might be and worrying about things.
- It may have helped to ease anxieties about how my illness would affect my dealings with work colleagues, friends and some family members.
- Yes it would have helped greatly. I have a good support network of family & friends but as I do not like to worry them, having somewhere else to go would be beneficial. I am now nearly 3 years since diagnosis and when I go to the drop in centre with any concerns or worries I end up feeling like some kind of hypochondriac who is wasting their time.
- I may have been able to access support that I am unaware of.
- I might have admitted how afraid I was feeling instead of toughing it out and refusing to accept help – it could have made a big difference.
- Yes, I felt the world had stopped for me. I was overwhelmed and very anxious about the future and finances. I felt forsaken and alone.
- Could have helped access psychological support sooner.
- Signposting to charities/support groups could have been made – especially help with money worries and finding money to pay rent.
- Peer support could have been offered where available.

85% of respondents felt that enough time was given for the HNA and for understanding of their needs. When asked if there were any other comments to make about a HNA, patients responded with the following points:

- I feel that when diagnosed with cancer that the patient is handed a pile of leaflets and booklets but really one is reeling from what you have just been told and not ready to take in information that isn't relevant at that time to the treatment process.
- I had great worries about my finances and at the end of it all thrown out to cope alone, I'm sure I had something similar to post traumatic stress disorder.
- If I had a HNA it was right at diagnosis which is why I'm unsure/can't remember for certain if I had one. I feel it should be done at every clinic appointment (or accessible at any time digitally) as patient needs can change from appointment to appointment.

Care Plans

Patients were asked if they were given a copy of a Care Plan following their Holistic Needs Assessment, if this was shared with their GP, what the benefits were and how it could have helped if they did not have one. 15% of patients reported that they received a Care Plan - indicating that of the 28% who had received a HNA, around half of these were given a Care Plan and half were not. 57% said they did not receive a Care Plan and the rest were not sure. 12% said that a copy was also sent to their GP. In terms of how useful Care Plans were to patients, they reported:

- It provided me with the details of my treatment and it meant I was able to easily copy and give these to the relevant people when needed.
- It was helpful explaining things to my employer.
- Not particularly useful. The district nurse looked at it once, but it hasn't been used since, nor updated. Suggestions were not effective.

Other comments about Care Plans included:

- I'm not sure if by Care Plan you mean booklets. I got a carrier bag full of booklets.
- I can't remember if I had one and what with the huge volume of information to take in and literature handed out it would be best to access this digitally along with other important

treatment information (like a patient passport).

- I didn't want a copy, I wanted to just be in the hands of the team. We had decided between us what would happen. That was fine by me.

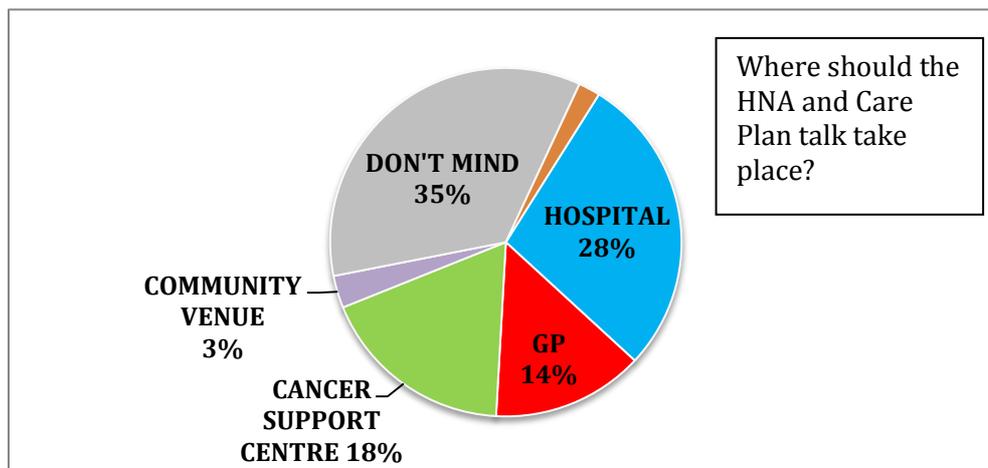
Patients were asked how a Care Plan might have helped them if they did not receive one. Responses included:

- They are a good idea – it would have given focus.
- I'm sure it would have been useful to have had this.
- I think that they are a great idea if there is only one plan and if it's available across all agencies.
- Again a Care Plan would be best accessed digitally for patients, HCPs etc. It's hard to remember what bit of paper is important and with so much information to take it having a digital plan won't get lost.

Patients were asked for any other comments regarding Care Plans and the following points were raised:

- Care Plans should be issued in the hospital and discussed again with the GP to reassure people.
- From the ward I was told it was Macmillan that gave a Care Plan out. At a busy time neither the ward staff nor Macmillan people were available to do this.

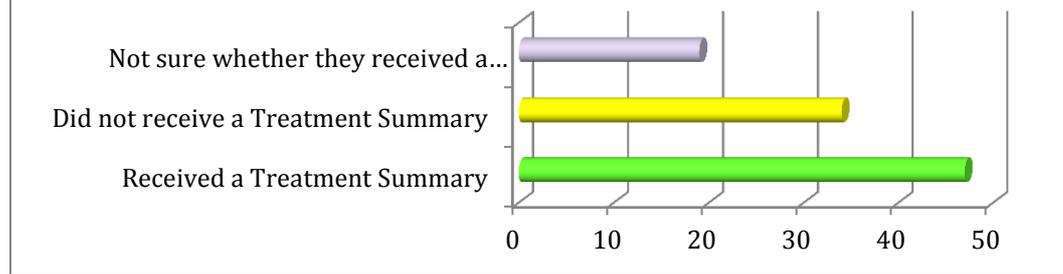
Patients were also asked where they would prefer to have their HNA and Care Plans talk and who should do this and this is demonstrated in the chart below. 36% of people said they would prefer their CNS to carry out the HNA and write the Care Plan and 26% said they did not mind who did this.



Treatment Summaries

Patients were asked whether they received a Treatment Summary, who this was shared with, the benefits and what would have been the benefits of having a Treatment Summary. The findings regarding who received a Treatment Summary, are shown in the bar chart below. 31% reported that a copy had been sent to their GP, though 62% were not sure about this.

How many people received a Treatment Summary?



Patients were asked how a Treatment Summary helped them and what difference it made and the following points were given:

- It allowed me to understand the whole process and gave me helpful tips as regards how to keep in better shape and live more healthily. I have used parts of this already and refer to the advice regularly.
- It served as a point of reference and provided information I was previously unaware of.
- I was able to provide information to the relevant people about the treatment I had received.
- I know exactly what is happening to me and the way forward. I am included in the decision making with regard to chemo. If I don't understand the terminology the doctor at the hospital will explain it to me.
- Provided me with current relevant information.
- It gave me a starting point for finding out more information, as initially it was difficult to come to terms with the diagnosis, and yet to not have active treatment or know when this may be with an advanced stage cancer.
- You don't always take everything in, and having a written summary helped.
- It reminded me of the processes I had gone through.
- For giving up work and claiming my pension early, it helped.
- Written information to read at a later time. Not always able to fully take in verbal information at one time. Opportunity to find out more about things I didn't understand.

Some other points about Treatment Summaries were also raised:

- I know I got a letter saying what treatment I had had but nothing about side effects or any further things to look out for.
- Was given a plan of treatment but not a summary afterwards.
- Made little difference but interesting to have.
- It only contained information on my treatment so was not really helpful.
- Very little use - got it after a while, not as it was needed.

Patients were asked how a Treatment Summary could have helped if they did not receive one and responded as follows:

- Could have been very motivating.
- Useful information as to treatment received and what to consider or look for as signs of reoccurrence of cancer.
- If I had one it would help me to share with other HCPs especially when admitted out of area whilst on holiday.
- I would feel more involved in my treatment and feel more confident about it.
- I would have felt less 'abandoned' and my experiences through treatment (blood clots and bad radio burns) would have been recorded.
- It would have my side effects written on it which would help me to explain things clearly to any health care professional who is treating or looking after me. It would help me to remember and know with certainty what medication I was given etc.
- Everything in one place - clear, concise communication for my patient record. There were

- examples during my treatment of lack of communication between the hospital and my GP.
- I'd have been more aware of help and support I could access and ask my GP for help.
 - I would feel confident that everything was captured in case it happens again.
 - It could have helped alleviate concerns about incontinence and erectile dysfunction.
 - If received when it should have done, it would have made things quicker and safer all round.

Cancer Care Reviews (CCR)

8% of patients reported that they received a CCR at their GP surgery and 75% of patients reported that they did not – the rest were unsure. Of the patients who received a CCR, one third of people made an appointment themselves and one fifth were invited by the GP or surgery staff to come into the surgery for a CCR. Almost half attended for a specific CCR appointment and a quarter were attending for a routine appointment. 80% of CCRs were done face to face and 20% on the phone. 80% were also completed by a CNS, suggesting these may have been Leeds patients accessing the Macmillan funded CCR pilot in several Leeds GP practices, whereby a CNS carries out CCRs. The other 20% of those who received a CCR ticked 'other person' rather than a GP in response to a question about who carried out the CCR, indicating that none of the 86 patients who completed the survey had a CCR with their GP.

When asked about the benefits of a CCR for patients who had one, the responses were:

- It helped me to have confidence in what was happening.
- Just to let me know what to expect.
- Helped manage the depression and anxiety that the cancer treatment and complications caused - help to sort medication may be of use.

People who did not have a CCR were asked how this could have helped and what difference it could have made and the responses were:

- Would have been interesting to talk through and establish GP care.
- It would have been good to discuss any anxieties or concerns about any ongoing symptoms.
- It would have at least informed me that my GP knew what was happening to his patient.
- An acknowledgement of everything I'd been through and a commitment to ongoing support if I needed it.
- I might have felt less 'abandoned' at the end of my treatment and reassured that my GP had the full picture.
- At that point, it might have helped me in coming to terms with how I was feeling about the points mentioned previously. I had felt very alone for months after my diagnosis.
- There are always questions before, during and after treatment, and it would be helpful to talk to a professional to get answers to questions. Instead I used the internet.
- It would have been great to have talked through my concerns and further health issues following cancer treatment. If I'd had a designated health care professional at my GP surgery then they would know more about me so I would not have to explain myself every time I visit my GP.
- Ongoing support. After such intense support during treatment there is some anxiety about being 'left' to manage on my own.
- To discuss unsatisfactory response from consultants regarding the healing of the scar.
- It would help me because I do not like taking up time at the surgery for things I know are connected to my cancer/treatment. My GPs never seem to know what to do or how to handle such things.
- It would have been reassuring for me to know that my doctor was taking an interest.
- Knowing who to contact if one wanted to would have been useful.

Some other points about CCRs included:

- I think the GP is too remote from the treatment and the CCR should be undertaken by the Hospital cancer care team.

- I didn't have any contact with my GP throughout my treatment or recovery so I was unsure what they knew or didn't know.
- These need to be taken seriously as after treatment stops patients feel like they are just left to go it alone without any support and feel silly for keep going to their GPs for any aches and pains especially if they are not given the right treatment when you raise concerns.

Health and Wellbeing Support

Patients were asked the names of organisations they had been referred to who could help and support them and answers included the following:

Macmillan Information & Support Centre, Cancer Support Yorkshire, Breast Cancer Haven (hypnotherapy, reflexology, acupuncture and arm, back and leg massage), benefits advice, charities, Headspace, social services, Overgate Hospice, lymphoedema clinic, The Annette Fox Leukemia Research Fund, BRI Physiotherapy and church.

The survey then asked if there were any organisations patients wish they had been told about sooner and the responses were:

Beating Bowel Cancer Charity, Cancer Support Yorkshire, Breast Cancer Haven, Breast Cancer UK, Cancer Research, Turn2us website, Pelvic Radiation Disease Association, ED Clinic, social workers, The Brain Tumour Charity and Brainstrust, Womb Cancer Facebook group, Speech & Language Therapy, St Gemma's Hospice, counselling and the Macmillan website.

Several comments were made by patients regarding the feeling of a lack of support once cancer treatment had ended including:

- It is important that information about support groups is made available to cancer patients and that health care professionals are aware of these and the information is given to patients early on in their treatment so that they can start getting support sooner rather than later and suffering in silence.
- I've done most research myself through desperation and trying to get answers. Mostly online but I have also come across some charities through patient advocacy work.
- People with or in remission from cancer need more avenues of approach - just a friendly voice, not necessarily medical.
- The nurses are wonderful but very busy; it would help to speak to other people who have been there; gone through the various levels of treatment and are willing to sit and listen.
- On the whole (including seeing the cancer specialists) I feel that my care once I finished the Chemotherapy / Radiotherapy has been abysmal. I feel let down by the care system or care providers that I have had to deal with, all of which adds a level of stress that only someone who has been through it can understand.
- I think that patients that have required no treatment other than perhaps surgery and then check-ups get no support or know where they could go if they have queries. Maybe following up patients regularly should be part of the service - this could be as easy as an email asking if the patient is OK or is there any support they need.
- Please give patients support after treatment has finished or make sure they are aware of local/online support groups. Cancer does not just go away after treatment has finished, there are always the worries and stress of it coming back and dealing with the after effects of treatment and the side effects of hormone treatment which can be debilitating in some cases and cause depression, anxiety and sometimes cause relationship breakdowns.

Additional Patient Comments

Patients were also asked if they wanted to make any additional comments at the end of the survey and some responses were:

- I am extremely grateful for the services that I received - throughout my illness I received nothing but kindness from the people who I met.
- The staff at the Macmillan Unit where I had my treatment, were very kind and quite caring. I

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am very surprised that I was never given the information about the Cancer Recovery Package. It would have helped enormously on my return to work.

- I am sincerely grateful to all those in the NHS who helped and cared for me during my journey with cancer. I am grateful and blessed to be alive and living my life.
- We must ensure that patients receive a recovery plan and have the mechanism in place to review and sign post patients every six months to support groups or activities.
- I would love to take part in being a patient partner and have seen this in other areas of the UK but not LTHT. I want to use my experience to improve services but if these opportunities are there, they are not very accessible/well communicated. I think there are a huge amount of patients like me who would love to help but just aren't given the opportunity. Thank you for doing this survey!

Conclusion and Next Steps

The West Yorkshire and Harrogate Cancer Alliance is committed to ensuring patients, carers and others affected by cancer are given an opportunity to share their experiences, views and recommendations in order to inform change and improve services across West Yorkshire and Harrogate. This survey was a way to collect information and feedback from patients about which parts of the Recovery Package they had been offered, how this had helped them or could have helped them, and what health and wellbeing support was offered during or after treatment. The survey was primarily intended to acquire patient quotes and insight around their experience of the Recovery Package, to feedback to cancer professionals attending the Cancer Alliance events held in 2018 and inform and drive the implementation of the Recovery Package consistently across West Yorkshire & Harrogate. Indeed during these events, several comments were included in attendee feedback around the significance of considering things from the patient's perspective:

- "It was helpful to see the patient views of HNAs and Treatment Summaries."
- "The session showed the impact on patients if there is no communication at the end of treatment."
- "The session demonstrated how important the implementation of HNA and TSs are for patient care."
- "The Recovery Package should be driven and centred around the patient."

The statistical data from the survey has also been extremely useful and gives an indication that there continues to be significant variation across West Yorkshire and Harrogate in terms of patients being offered elements of the Recovery Package such as Care Plans and Cancer Care Reviews, which will be addressed through the Living With and Beyond Cancer programme of work.

Both the quantitative and qualitative data will be used by the Cancer Alliance to progress the implementation of all aspects of the Recovery Package across West Yorkshire and Harrogate, using the patient voice as a driving force for change and service improvement. The Cancer Alliance would like to sincerely thank all of the patients who took the time to complete the survey and share their views and experiences with us. We are also grateful that 26 of the patients provided their contact details to engage further with the Alliance and several of these people who also attended the multi professional event on the implementation of the Recovery Package on 11th October, representing the patient voice, as well as other Alliance engagement events. Such involvement with patients will enable us to continue to improve and develop services for the benefit of other patients affected by cancer across West Yorkshire and Harrogate.

West Yorkshire & Harrogate Cancer Alliance, 26.10.18

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