

Wessex Cancer Alliance Patient, Carer and Public Experience and Engagement Literature Review

August 2019

Contents

1. Introduction	4
2. Summary of findings	5
3. Findings.....	7
a) Prevention and Screening	7
1. Awareness	7
2. Engaging with Black, Asian and minority ethnic communities	9
3. Communication	10
4. Reasons for not attending screening.....	11
b) Earlier and Fast Diagnosis	15
1. Communication	15
1. Delays and waiting times.....	16
c) Access to Optimal Treatment.....	17
1. Communication	17
2. Tailored support	18
3. Clinical Nurse Specialists	21
d) Personalised Care (including End of Life)	22
1. Communication	22
2. Information	25

3.	Pain management and fertility	27
4.	Ongoing support and after care	27
e)	Specific feedback from seldom heard communities	37
5.	Conclusion	43
6.	Recommendations	44
	Appendix A: Methodology.....	45
	Learning from this process	46
	Recommendations	48
	Appendix B: Useful information and resources for engagement.....	49
	Appendix C: Results from the 2017 National Cancer Patient Experience Survey	50
	Acknowledgements	56
	Contact us	56

1. Introduction

The Wessex Cancer Alliance asked Wessex Voices to research and produce an independent literature review of recent local and national patient, carer and public experience and engagement to inform their response to the NHS Long Term Plan.

Whilst we only had a short space of time to gather and analyse information we feel that the review identifies and draws together in one place useful, common themes from this intelligence. (For more information about how we did this and our recommendations resulting from it see Appendix A).

Our findings are documented under the headings of “Prevention and Screening”, “Earlier and Fast Diagnosis”, “Access to Optimal Treatment”, and “Personalised Care” (including End of Life), as set out in the Cancer Alliances Five Year Deliverables guidance.

From our findings, we identify gaps in patient and public involvement (PPI) intelligence that may need further exploration. We draw out lessons learnt from the review exercise; make recommendations to improve intelligence sharing around cancer related PPI; and make some recommendations to the WCA about retaining a strong commitment to meaningful coproduction across all areas of its future work to enable it to be person-centred.

2. Summary of findings

- Some people are still not aware of the links between some cancer risks and the disease itself. There is also confusion about awareness of, eligibility for, and processes around screening programmes. Both are particularly true for older and Black, Asian, minority ethnic and refugee people.
- Barriers to screening vary, from the practicalities around appointment convenience; to embarrassment as the nature of screening is that it is very personal; to fear either from a past bad experience or of the results.
- Good communication and signposting to relevant information are the two key issues that come up throughout people’s cancer journey. People want more information on treatment options and alternatives, side effects and medication. They also want good access to information about concerns other than medical care. Information and sign posting at all points of the pathway with relevant, accessible information (a one stop shop) is seen as vital.
- While it may be difficult to anticipate what support people will require during their cancer journey, and whilst needs vary at different stages and depending on individual circumstances (age, gender, ethnicity, socio-economic status, etc) people value being prepared for their experiences.
- People want clear, easy to understand personalised care plans covering the whole pathway and into after care and returning to “normal”. It was clear that there is little recognition by patients of what a care/treatment plan is and why it should be provided. The need for improved communication between professionals and services is often mentioned by patients.

- Many people feel their emotional needs through the cancer pathway are not being met. This has a significant impact on recovery and future well-being.
- Overall people are happy with the actual care and treatment they receive whilst in hospital, with much praise in general for staff and carers.
- The level of support people need during their recovery varies enormously, as does the length of time that support needs to be in place.
- End of life care needs to be tailored to meet the needs of individuals and their circumstances.
- Seldom heard groups experience disadvantage in their access to engagement opportunities and cancer services and therefore need specific consideration when designing and evaluating services.

3. Findings

We have identified common themes from the experience and engagement intelligence and set these out under “Prevention and Screening”, “Earlier and Fast Diagnosis”, “Access to Optimal Treatment” and “Personalised Care” (including End of Life). Please note that although much of the feedback could be placed under more than one heading, we have attempted to use the most obvious one to avoid duplication.

a) Prevention and Screening

Common themes:

1. Awareness
2. Engaging with Black, Asian and minority ethnic communities
3. Communication
4. Reasons for not attending

1. Awareness

- Many older people are not aware they are still eligible for screening programmes, or know they should be screened, or think it’s worth attending over a certain age. Macmillan interviews with patients identify there is confusion around the role of screening for cancer in older people.

People don’t understand the age ranges for screening and the options that exist for those above the screening age range to ‘opt in’ to screening. This is supported by Wessex Voices engagement work around breast and cervical screening. There is also be confusion amongst some healthcare staff.

- Feedback from work undertaken by Macmillan suggests that people do not understand the link between cancer and age either. “The overwhelming majority of all age groups over 55 both living with (90%) and living without (84%) cancer do not think that cancer is an age-related disease. This is despite a wealth of evidence that shows older people are at greatest risk. Instead, the qualitative research suggests that people perceive diagnoses of cancer as random, unexpected events that can affect anyone. The fact that older people do not realise that their age is a significant risk factor for cancer may have implications for efforts to encourage earlier diagnosis of cancer; if people do not believe they are at greater risk, this may impact upon their help seeking behaviour.”
- Some feedback from young people nationally suggests that many feel cancer doesn’t really affect them so they don’t see the necessity to go for screening.
- Further feedback from some young people about their awareness of cancer discusses the use the use of sunbeds. They advised they do not feel that they can be taken seriously as a cause for cancer because they are legal and often no health warnings are provided when they are used, as opposed to cigarettes.
- Some people with cancer, who are still smoking, advise they need signposting to support and guidance.
- Feedback both nationally and locally suggests if there is greater awareness of the signs and symptoms of cancer will seek help from services and go for screening. There is still a lack of understanding about the progress that has been made on cancer outcomes and treatment, and more needs to be done to raise awareness of screening programmes and provide information about what happens at screening appointments.

- People who have had bad experiences of screening services are more likely to negatively influence their communities and social networks.
- Patients feel more could be done by GPs working with local communities to embed messages about healthy living, life choices and screening programmes.
- Women advise that they are more inclined to attend screening tests when prompted or reminded by their GP surgery as it this indicates that screening is important.
- There seems to be a lack of understanding around what screening services are, what is available and what different procedures involve. This was particularly true of feedback received nationally from BAME communities, asylum seeker and refugee groups.

2. Engaging with Black, Asian and minority ethnic communities

- When engaging with BAME communities, such as around breast health, many organisations have acknowledged that getting out into these communities where people live, work and network is key.
- Feedback from many BAME groups, especially women’s groups states “grouping together” women from different BAME backgrounds does not work. For example, Chinese women are often more reserved and less interactive. See below for different examples.
- Feedback received through Jo’s Cervical Cancer Trust shows Bangladeshi women highlighted that many of them stay at home and are not as proactive in the community compared to other groups. “They do not visit many places,

apart from schools to pick up children and their GP practice. Thus, there is a real need to reach out to women within their homes. Women highlighted that face to face interventions were the preferred method of accessing information and improving knowledge, especially via GP practices.”

- Further feedback from Jo’s Trust states “Whilst all Bangladeshi and Indian women believed that cervical cancer can be treated, 30% of Pakistani women disagreed. Despite this, Indian and Pakistani women had better levels of awareness about cervical cancer compared to Bangladeshi women.”
- Although all prosthetic breasts are offered in a diverse range of colours and available to all skin types, women from BAME communities advised it would be good to see what breast abnormalities look like on darker skin. This would help with awareness and screening.
- Travellers, refugees, asylum seekers find it almost impossible to get information or reminders about screening when they don’t have a set address or are not registered with a GP.

3. Communication

- Feedback from Eastleigh Breast Cancer Support Group states that when patients are in the process of having breast cancer treatment they can still get invitations to screening, which “adds insult to injury”.
- Not all patients with COPD are told their annual review includes screening for lung cancer and most with this condition would prefer to see the same nurse/doctor for all appointments.

4. Reasons for not attending screening

- People question the effectiveness of screening programmes e.g. people know of others who have had mammograms and cancer has not been diagnosed.
- People often stated that a fear of what may be found at/from screening prevents them from attending (they would rather not know).
- Eastern European women gave these reasons for not going to smears:
 - They are tested “back home” when visiting
 - Long appointment times
 - Different methods of screening in their home countries (seated not lying down) or more detailed tests
 - Language barriers
 - Fear of having a bad experience or repeating such an experience.
- Other barriers to cervical screening for BAME and seldom heard women are:
 - Sexual behaviours and discussions about issues, such as cervical cancer, are sometimes not discussed at all depending on culture
 - Often there is stigma and myth e.g. “cervical cancer is something you get because you have done bad things”.
- Older women from seldom heard groups state the same reasons for not attending cervical screening:
 - Discomfort
 - Embarrassment
 - Concerns about the procedure and what it involves
 - Negative perceptions of health professionals

- Lack of trust in the results
- Different beliefs and negative experiences.

- In general, older women from all communities gave the same or similar reasons for not attending cervical screening. These are the main issues:
 - Having a previous bad experience
 - Worry about the results
 - Difficulty accessing appointments when working
 - Not being convinced of the evidence for screening
 - Lack of awareness of screening programmes for older women. Those particularly at the upper age limit of screening programmes are confused whether they are eligible, they don't think they need to go if they are or have been through menopause or had a hysterectomy.

- Feedback from younger women on the reasons they don't go for screening are the same, but a survey of 25-29 year olds by Jo's Trust also found:
 - They are just put it off when they are well and don't have any problems
 - Many (72%) don't feel comfortable getting undressed in front of the staff
 - Many (70%) don't think screening reduces the risk of cervical cancer.

- Jo's Trust also found that 75% of women surveyed who have experienced sexual violence have not attended or have delayed cervical screening because of their experiences. "Over half of those surveyed said there was no support to help them prepare for the test with lack of understanding or sensitivity among health professional cited as a barrier to attending. 86% of survivors want specific information about going for a test after having experienced sexual violence. A third said they would benefit from having a card to show a doctor which explained their experience without having to talk about it."

- Barriers to attending breast screening include¹:
 - Not receiving invitation/reminder letter
 - Venue not convenient
 - Venue not disabled friendly

“I am a disabled person. On my last screening the pictures collected were not as good as they could have been. I found it difficult to position myself at the correct angle. I don't know if there is an alternative way to do the screening.” And “I used to go until they modernised the equipment which does not allow for me to use my electric chair during the procedure as the old one did. I have now been excluded through no fault of my own. As I have had cancer extensively in 2005 I am annoyed about this exclusion but I cannot transfer into another chair for physical reasons.”

- Embarrassment
- Fear
- Thinking it's not important
- Having a previous painful experience
- Not feeling valued

“I felt it was efficient, professional, 'conveyer belt fashion' and not a very empathetic experience. Not a criticism as they have a large number to get through but just a note as many may require more reassurance, and if their previous experience was not reassuring they may not return again.”

¹ Doc 36 “Eastleigh Breast Cancer Support Group”; Doc 61 “WV Why Women Don't Go”; Doc 74 “Healthwatch Bristol Breast Health Awareness in the BAME Community”; Doc 82 “Healthwatch Bristol - Bristol & Avon Chinese Women's Group”; Doc 89 “The Pink Sister's Cancer Journeys”; Doc 111 “Breast Cancer Now - Rebuilding my body”

- Reasons for not attending bowel screening included:
 - Fear
 - Embarrassment
 - If “symptom free” why do the test
 - Finding the test dirty and the instructions are not clear. Providing gloves would help.
 - People with sight problems find using the bowel cancer testing kit problematic.
 - If already being treated for another form of cancer many people think they don’t need testing. This also came up with other cancers. People assume that if you are being treated for one form of cancer the hospital will be checking for everything.

b) Earlier and Fast Diagnosis

Common themes:

1. Communication
2. Delays and waiting times

1. Communication

- Many young people say they feel they are treated differently by different health professionals and are often not listened to. Seeing the same GP gives young people more confidence in accessing services. Waiting a long time to see a health professional puts young people off accessing services. Young BAME people talk of the stigma or taboo relating to cancer within the Asian community and that no one talks openly about it.
- A 2016 patient survey shows 23% received no explanation about their x-ray or scan. 15% waited over 4 weeks to hear results and patients do not understand the role radiologists in their diagnosis and treatment.
- Feedback suggests there can be conflicting information between services and professionals especially during diagnosis and initial care.
- Many people advise it can be difficult to absorb all the information given at this stage, therefore making informed decisions and choices harder, especially if you are doing this alone. Also see feedback about advocacy under “Personalised Care/Ongoing Support and After Care”.
- At diagnosis people would like tailored information, follow up and support.

1. Delays and waiting times

- People cited problems with getting initial GP appointments and often not receiving tests or referrals for tests until after seeing a GP numerous times.
- People often feel alone and unsupported after diagnosis. A majority feel overwhelmed by their diagnosis. There is a need to give people time to “take things in”, then have support to explore information and ask further questions. Factors, such as emotional state, affect the processing of information so providing it at the wrong time or in the wrong way may mean it is not processed effectively.
- Patients often state concerns about the time it takes to receive test results.
- Results from the Healthwatch Long Term Plan (HW LTP) surveys across Wessex suggest people describe the time taken to receive a diagnosis, and the wait between diagnosis and treatment, as slow or very slow.
- There is a disparity between the amount of time that people have to wait for treatment to start, depending on the hospital and specific cancer.
- There are often delays in transferring medical records between services and/or sites. Many people are not being seen by specialists within the guideline target times.
- Following a patient’s scan/x-ray etc there can sometimes be a period of time where communication with the patient goes quiet. This period can be very distressing for a patient who is awaiting a diagnosis. Communicating to the patient what is happening and when they can expect to hear would help patients feel less anxious.

c) Access to Optimal Treatment

Common themes:

1. Communication
2. Tailored support
3. Clinical Nurse Specialists

1. Communication

- There is a feeling of a “lack of joined up services” meaning patients are often wait in clinics for a long time or need to make multiple journeys to hospital to see various specialisms, oncology, radiology, outpatients, scans, blood tests etc, which they feel could have worked better together.
- Patient information sometimes can’t be easily transferred between hospitals, causing delays and stress for patients who have to access multiple Trusts.
- Results from the HW LTP surveys locally suggests many people find it difficult to access ongoing support after diagnosis. Just half said they received timely and consistent communication from all services but some patients felt “out of the loop” with professionals communicating with one another but not them. Those with cognitive difficulties were often even more alienated from involvement in their own care.
- Feedback received through Macmillan states that 71% of people living with cancer in the older retired age group feel that healthcare professionals know what’s best for them when it comes to their care, compared with only 58% of those in the working age group. This supports the general findings that people below retirement age tend to want more information from the healthcare professionals treating them.

- Cancelling of appointments at the last minute or with no explanation cause stress and anxiety.
- Many people say that understanding what is going to happen/may happen to them is vital in order to be emotionally prepared for treatment.

2. Tailored support

- Most feedback about staff and the actual medical care and treatment is generally positive.
- People state they wish to have more support options from diagnosis. Often information is provided too late or not given and patients find out they have other treatment options by chance.
- Many people said they would have liked a period of time after diagnosis to come to terms with things, research options and make decisions with the support of healthcare staff rather than having to make “snap” decisions.
- Feedback from the Multidisciplinary Diagnostic Centres pilot sites shows the role of the ‘navigator’ receives extremely positive feedback from patients. Patients referred through the MDC pathways also report high levels of satisfaction with how all the people caring for them work together to give the best possible care. (Note: the MDC service has a number of features that would not be a normal part of routine cancer pathways, such as the navigator role. Although the exact nature of this role varies from site to site, they all share similarities in that they provide support and are a contact point for the patient as they go through the pathway).

- The importance of keeping well for many patients (see WESTFIT pilot) is seen as potentially reducing the length of time in hospital, helping recovery and moving on afterwards. People want more of this support and help.
- Many patients state they would be/are happy to receive follow up care by phone, especially to review wellbeing and especially from nurse specialists who know the patient and the patient history. This reduces waiting times at clinics and unnecessary journeys.
- Nationally, patients have said they have no choice but to attend Emergency Departments occasionally and there should be a way to allow them to “bypass” this if they are already receiving treatment for cancer.
- From the AllCan international survey, UK patients said that the main inefficiencies in their experience are:
 - My initial cancer diagnosis: 36%
 - Dealing with ongoing side effects: 19%
 - Dealing with the psychological impacts: 15%
- Although this feedback could be placed in other areas of this report it all relates women who have had or are undergoing treatment for cervical cancer collated by Jo’s Trust, so feels more appropriate to keep it all together here:
 - Almost all said that while the diagnosis meeting was difficult, the consultants they saw were sensitive at the time of diagnosis. Many mentioned factors which could make diagnosis slightly easier and potentially less traumatic including: who is present at the time; the manner in which a diagnosis is given; how partners or family members are treated during diagnosis; and what happens immediately afterwards.

- The initial diagnosis meeting is the first opportunity for clinical staff to provide information and support materials. Some women felt bombarded with too much information, others were happier to take information away. The role of a partner, friend or family member was critical, with some saying that they were unable to absorb everything initially so the person accompanying them was able to do this for them.
- 74% said contact with their CNS was important. However, there were some women who found the initial presence of the CNS, prior to their diagnosis, was alarming and upsetting. Spotting a CNS in the room was an indication that bad news was going to be given.
- 75% the women said that an ongoing relationship with their CNS was important. However almost half (47%) would have liked to have had more contact with theirs. Often this was linked to CNSs being busy and rushed or overworked. Nearly a quarter had little or no contact with a CNS.
- Almost all the women reported feeling ‘safe in the hands’ of the medical professionals looking after their care and treatment, often giving this as the reason for not seeking a second opinion on their treatment options.
- Two-thirds (63%) said that they did not need further treatment following the surgical intervention they received. However, the long-term effects of treatment were something that many of the women were now dealing with, for example: isolation, sickness, fear and tiredness.
- Each woman had a different experience of treatment with the impact often influencing physical, emotional and practical aspects of their lives. For some the frequency and intensity of the treatment resulted in significant changes to their day to day routine. For others, family or work

life were where they felt the most disruption or pressure.

- Only half (43%) said that their level of care throughout treatment and follow up remained consistent. Almost a third (29%) felt there was a lack of psychological support after their treatment had finished.
- During treatment, women value the support provided by external organisations, such as cancer charities.
- While each woman had a different experience depending on their circumstances, treatment and stage of cancer at diagnosis, some common themes came out. These included: loss of fertility; the impact on relationships, including sex and intimacy; changes to employment and finances; and the impact on families and children.

3. Clinical Nurse Specialists

- Not everyone had access to a CNS or case worker or key worker but access to a CNS is seen as central to many people for support.
- There are some reports of difficulty in accessing specialist cancer nurses, appointments are often cancelled; and patients feeling “out of the loop” once they are “signed off”.
- Some patients opt to have private treatment. These patients then become unclear about who to contact within the NHS and CNSs no longer provide pro-active support and advice.

d) Personalised Care (including End of Life)

Common themes:

1. Communication
2. Information
3. Pain management and fertility
4. Ongoing support and after care

1. Communication

- Many people express concerns over language barriers making it difficult to access information and support. This feedback comes from people who don't have English as their first language but also from people trying to understand jargon and “medical speak”, those with learning difficulties and people with sight or hearing difficulties.
- People want to be listened to and taken seriously. Feedback suggests that GPs often defer to specialists, which means if a diagnosis is wrong or the patient has concerns they feel they have no option to talk to someone else.
- The Dorset survey of patients with lung cancer suggests experiences of the same service differ between Trusts, mainly in areas of provision of information and access to a CNS. The need to be kept well informed throughout the whole pathway is paramount.
- Many people still prefer postal communications, although often letters don't arrive until close to appointment times. Letters are often difficult to read (because of medical terminology) for many people.

- People need to know they can bring someone with them to appointments should they wish to. This is often something patients find out afterwards.
- Views of carers of patients with lung cancer in Dorset suggest there is still room for improvement. Issues that are highlighted are: whether carers have all the information they need about support and self-help groups; whether they are given enough opportunity to speak to doctors/nurses on their own; whether they have sufficient help to cope with worries; and whether they are given enough information about what to expect when caring for their loved one.

Views are slightly better regarding whether they are given enough opportunity to be involved in decisions about the person's care. Some said they had no point of contact or communication about what was happening between diagnosis and start of treatment (delays etc). More joined up services are desired but high praise was given for most staff when it works it works well:

“I cannot speak too highly of every aspect of my wife's care. In particular the speed with which she was called into DCH as soon as her scan had been analysed - her almost immediate transfer to Poole for radiotherapy - early (and subsequent) appointment with consultant - excellent and responsive support from the lung cancer specialist nurses - the effectiveness of the treatments given - the involvement of the GP and the various NHS support services, i.e. district nurse, OT, physiotherapist, support equipment, and links with the Macmillan and Weldmar nurses - the efficiency with which appointments have been arranged, and on the few occasions necessary rearranged - the joined up way in which the system as a whole has worked. Thank you.”

“It is difficult to give a fair assessment of the service with just a few boxes. My wife's treatment involved three hospitals, 6 or 7 different wards, A&E in Dorchester (several times), and of course dozens of nurses and doctors and other hospital staff. Not to mention district nurses and GPs in the community. The care my wife received varied from the appalling to excellent and everything in between. Part of the problem was the ridiculous system - trying to get help via 111 service and being directed to A&E - waiting on trolleys for hours. On the other hand many of the staff - nurses doctors auxiliaries etc were amazing. Some (a few) were very poor in terms of their attitudes, and apparently, their training. Another issue was a deficit in effective communication between different teams, wards etc. On occasion I and my step-daughter had to inform nurses of the correct care to be given as advised by consultants as the nurse had failed to read my wife's notes. On another occasion, after 4 or 5 hours waiting on a trolley in A&E, my wife was moved to a ward which had no pillows. I had to drive home to get some pillows for her. This sounds very negative but of course in the end my wife has made a full recovery and for that we are very grateful to all those who helped her. It is just a shame that the whole experience was made much worse than it needed to be by some people and some aspects of the service. I'd also like to mention the team at Weldmar Hospice who helped us a lot and were wonderful (but at first we didn't know we could use them). What I believe would have made the whole process better, and would have reduced my wife's suffering and my stress, would have been to have one person appointed to oversee all her care and treatment. I think there was a lack of care planning. If a better care plan was in place, coordinated by one person, we would have had better information, we would have known that we could have a hospital bed, we would have known we could access Weldmar services etc. As it was everything seemed to happen in a haphazard fashion. We found out things by chance.”

2. Information

- There is often a void between the point of diagnosis and the start of treatment. Patients often suggest this time could be used to “prepare” the patient/family for what is to come. For example, information on well-being and support in the community.
- Access to information and support is inconsistent between service providers and also within cancer specialties (This is also seen in the NCPES results).
- The type of information patients say they want often includes practical support, emotional support, information about support groups (during and post care), information on the long term side effects of treatment, information about diet and nutrition, how to claim benefits, free prescription charges, clinical trials, support for carers and information on bereavement support for families and carers.
- Information needs to be accessible for all in a range of formats with continuity across all providers and services.
- Some cancer specific services have patient information booklets and information, some don't. Some are better at ensuring patients receive information. This seems to be confirmed from the NCPES results.
- Although young people may prefer health information online and via social media platforms they still want the same kind of information i.e. about cancer and what to look out for, lifestyle choices etc. They often advise there is not enough cancer information aimed at younger age groups.
- Feedback about travel and transport issues comes up many times. Many people are not given enough information about what to expect on travel and

assistance, and how travel can affect them whilst undergoing treatment. Regular travel to ongoing treatment can be expensive and some people do not attend all appointments due to travel issues and costs. This is especially true for those receiving treatment and care at multiple sites. There is often limited awareness about charity and third sector travel options.

- Some patients say badly photocopied information leaflets are received with their appointment letters. This gives the impression they are worthless, which they felt was a very negative message to receive prior to any treatment. Printed or well photocopied leaflets would make a difference.
- Many people feel there is a lot of information to take in about treatment and options and it can often be confusing. Macmillan are often cited as giving the best information (as well as support and guidance).
- Patients and families often express a sense of information overload at times during their treatment. The right information given at the right time, in the right way is something that needs to be tailored to the individual.
- This is from the Dorset lung cancer carer survey but could easily relate to other cancers: “Whilst I was made aware at the diagnosis stage that help with counselling/ support group was available and leaflets available, this has not been mentioned again. Feels a bit like because I’m an intelligent and professional person I’ll seek out help if necessary. However you don’t always know what you’re not aware of or don’t know. I haven’t been given any information about what to expect as a carer or an opportunity to speak to a doctor/nurse on my own, although I feel it would be possible to request a meeting.”

- [Penny Brohn](#) receives positive feedback for ongoing health and wellbeing information on diet, exercise and mindfulness.

3. Pain management and fertility

- Access to pain management is highlighted by patients with all cancer types.
- A Shine Cancer Support survey (for people with cancer between 20-40 yrs old) states 50% of respondents didn't feel they were adequately supported to preserve their fertility before they had treatment. CEO Ceinwen Giles adds "Doctors and patients very often have different priorities when cancer is diagnosed but they don't tend to talk to each other about it."

4. Ongoing support and after care

- Some people find adjusting to life after cancer treatment relatively straightforward, but one in three people (34%) struggle with their physical wellbeing up to two years after treatment ends. Problems such as incontinence, difficulty eating, or breathlessness can make people feel as unwell as they did during treatment.
- The emotional impact of cancer should not be understated. 30% of people who have completed treatment in the last two years say their emotional wellbeing is still affected. People frequently experience feelings of depression and anxiety, particularly around not being able to 'get back to normal'. Instead of elation or relief when treatment is over, they can feel lost and find it hard not to worry that their cancer might come back.
- Current aftercare does not consistently provide people with the support they need after cancer treatment. People often say that they have 'fallen off a

cliff' and don't know what to expect or where to get help.

- Over 80% of people facing physical difficulties in the two years after treatment say they have not been fully supported to get their life back on track. Similarly, nine in ten people whose emotional wellbeing has been impacted feel they have not had enough support to deal with this.
- Many of the common issues people face after treatment can be managed by the person themselves if they have the right information, tools and encouragement. For others, it may only take a little extra support to feel confident about managing their new reality and to overcome the issues they face.
- Most of the negative issues from the Dorset lung cancer patient and carer surveys are around post discharge and accessing help at home, where and how to get support and information about general living issues, not necessarily medical ones.
- Patients advise they often find it difficult to get GP appointments even for ongoing care.
- Feedback about [The Living Tree](#) self help support group (in and around Bridport) is very positive. Many people would like more statutory support for third sector organisations that play a huge role in giving information, support and advice during and especially after cancer treatment.

Many such organisations also run screening and awareness events (e.g. New Man Prostate screening support, and the Women's Institute looking at trying to improve uptake of cervical screening).

- Here is a national example showing how much the third sector can improve a patient's experience. "Chemogiftbags is run by a small team and lets people in Berkshire, who have Breast Cancer and are undertaking chemotherapy, know that there are people who care. The team produce gift bags, which consist of many items that might make chemo a little more manageable. They include cosy socks/slippers, blankets, flavoured teas, word search books, soft tooth brushes, a "Thinking of You" card and many more items. All items are donated by the public and businesses.

"Chemogiftbags came as a ray of hope for me it was like Santa came early. Having my whole family here when I received it, it shifted my thoughts from having no hope to knowing that people outside of my family were showing their support. I think Chemogiftbags are doing an amazing job of bringing hope and practical support into people's lives when they need it most. It is a great and needed charity for people who are in a bleak situation."

- Support groups, such as Breast Cancer Friends Hampshire, provide the sort of everyday help that a hospital can't really give but that has a huge impact on patients' health and recovery:

"The Facebook group Breast Cancer Friends Hampshire UK is a closed group that I joined just after diagnosis after a lady at work recommended it - it was the best thing I did! They helped me throughout chemo, surgery and rads - like my own personal support team - a wealth of information on hand 24/7 - always someone awake at 3am when the steroids kept me awake - issues of nausea, sore mouth and what foods to eat, not to take steroids after 2pm as you will be awake all night - paint finger nails dark to help prevent lifting, seroma after surgery, what is that?, bite the bullet and shave hair off to regain some control rather than waiting painfully for it all to fall out, free prescriptions card via GP, claim new style ESA benefit, keep a daily diary of

symptoms and food / medication times in case of illness and to help me plan for future chemo cycles, make a claim on your critical illness life assurance.... all of this was invaluable information and kept me going through treatment.”

- Macmillan’s Hope (Overcoming Problems Effectively) course receives positive feedback.
- Their research shows that older people are less likely to worry about requesting help and support. This is despite other research shows that they are less likely to receive support. “One third of respondents ... report a perception that older people receive less support than younger people. This suggests that appropriate support is often not available for older people living with cancer. Our interviews also suggest that older people may not be aware of the support that is available to them. Contrary to received wisdom, older people are more likely to be comfortable seeking help than younger people.”
- People would like somewhere to go (one point of contact) for help, advice and support for questions that do not need actual medical appointments. The Macmillan support helpline receives positive feedback although some people said it takes a long time for them to make initial contact.
- Findings from a brain tumour cancer patient survey show “... a substantial difference can be made to the overall patient experience if a person feels that oversight of their care lies in someone’s hands - a single, named individual; in the words of one respondent, that someone has ‘ownership’ of their care”.
- Advocacy is continually mentioned positively in feedback from patients, who may not have other forms of support, and families. The following patient experiences have been collated through the Older Peoples Advocacy Alliance:

“I needed somebody on my side to understand what I’d gone through and be there to represent me. My CNS was the most difficult person to get hold of. He was lovely but just too busy. I was frightened. I needed reassurance. When I read the leaflet I thought “Ah, somebody to support me”. Sam first came to see me when I was in respite. You don’t know what those visits meant to me to discuss ways forward and give me hope.”

“When I was discharged from hospital we were inundated with appointments for radiotherapy and meetings with consultants and we were suffering from information overload. Once again Dorset Macmillan Advocacy came to the rescue by providing an advocate who would come (and on some occasions take us) to our appointments to take notes about what was said.”

“Maddy, my advocate, first came to meet me and my wife at our home. She discussed with us what information we wanted to find out from the various consultations and she agreed to take notes during the meetings. It was agreed that she would prompt us if we hadn’t asked all the questions we wanted to. We later discussed the notes she had taken to ensure we had remembered everything and she left the notes with us for future reference. The consultants we visited were very open to the advocate being present during the consultation and made her feel welcome.”

“Judith, my second advocate, helped me complete Department of Work and Pensions (DWP) forms. If she hadn’t helped me, I’d have nothing financial to live on. Judith saw me really low. With Judith, I felt, “here’s someone that knows”. She’d been there with cancer herself and been through depression. She was vitally important to me. Because she helped me I was able to be in the support group for Employment Support Allowance. I had to put on the forms about the depression. The cancer was really bad and scary but coping with the depression was a lot worse. Judith helped me through that.”

- It is clear that having some kind of advocate can make a big difference to the experiences of patients and families. For example, the OPAAL Annual Report states that referrals from Macmillan’s helpline and support teams increased by 84% following a talk by peer volunteer advocates.

- Feedback collated through The Brian Tumour Charity, documenting experiences of young people with brain tumours and their families is set out below. Much of this could be relevant to young people with other cancers.
 - The mental wellbeing of a child with a brain tumour may be dangerously compromised if their complaints are not taken seriously in the critical period prior to diagnosis, or if their private fears and frustrations during and after treatment have no outlet. Meanwhile, siblings whose parents are necessarily consumed with caring for a sick child may also suffer significant emotional injury if their needs go unmet for long periods.

 - Few families affected by a childhood brain tumour are strangers to loneliness, and every family member may be touched by it in their own ways, at different times. A brain tumour brings its own inevitable burden of fear and pain - and parents and children alike may feel obliged to conceal or minimise their own feelings in order to avoid adding to this.

 - To properly address this, the negative emotional and social impact of childhood brain tumours must be treated as part a brain tumour diagnosis, deserving as much care and attention as the clinical dimension. A brain tumour affects the way a child or young person is able to interact with the world. Responding appropriately requires effort to understand the combination of practical and psycho-social needs this creates in play, rest, education and work, so that kindness and empathy also translate into proactive, person-centred intervention.

- Regular contact and follow up (e.g. via Weldmar support line) helps reduce feelings of chaotic and unplanned care. In general, feedback for Weldmar services all relate to patients feeling more positive, informed and able to cope better dealing with life. People want someone to talk to about issues other than their medical treatment - life in general and coping. The Weldmar themed Carer Experience Questionnaire 2018 shows all comments relate to help and advice provided leading to better informed carers, better able to perform their caring role.

- In general the type of information and support people want/need covers:
 - Help with finances or support and advice about where to go for help. This is often needed earlier in the patient journey, especially if it impacts on work or benefits. In 2012 Macmillan estimated that 91% of cancer patients' households experienced a drop in income. Apart from those who have already retired or been unable to work because of other illnesses, the majority of cancer patients and/or family members have to either stop working or reduce working hours.

 - Advice about free prescriptions or help with other equipment etc.

 - Emotional and psychological support at all stages through the cancer journey and post discharge to return to “normal” life. The Westfit pilot however shows people have mixed feelings about whether access to counselling is positive (the term counselling has some negative connotations, thus “mentally” fit for surgery rather than counselling may be a better term). There is also mixed feedback on when counselling should be offered, demonstrating this needs a very personalised approach.

- The importance of psychological support from a patient:

“Each time I met with my surgeon, I asked for a mastectomy to remove my unaffected breast. I felt that after chemotherapy, surgery and tamoxifen, I needed to regain control of my cancer and my future. However, my surgeon was not supportive of this course of action as she said she did not wish to remove a healthy breast. I reminded the surgeon that I had been told my affected breast was healthy tissue when it wasn't. Finally, after a year had passed, I happened to see a different surgeon who agreed to carry out the mastectomy on my unaffected breast. I felt that psychological support was not available throughout my treatment and I had to seek this out myself from charities. I find it much easier being flat than lop- sided and I feel that this mastectomy has helped to give me some closure on my cancer.”
- Complementary therapies
- Alternatives to conventional treatment with information and support provided at point of diagnosis
- Information about support groups
- Guidance and support to access appropriate and relevant online resources that have been checked and verified
- Guidance and advice on diet/nutrition pre and post-surgery/ treatment
- Support and information for keeping fit pre and post treatment
- Help with hospital parking and transport/access to services especially for people on low incomes. Patients often say they do not get enough information on their options and choices
- Support and information on how to make a complaint or raise a concern
- Support around financial issues, legal issues and housing issues, as well as day to day living with cancer and after cancer. For example, information about wig specialists; help with children and families; help with adjusting to life with and after cancer and managing at work, talking to employers and knowing your rights:

“When the acute treatment ended and I can never thank all involved enough - that’s when it hit me - I’d survived cancer but it’s far from over when the treatment ends, a rollercoaster of emotions, what happens next? Well, you still have appointments, but you go from the intense almost daily contact with the medical teams to every few months, to manage on- going side effects”.

“...things like neuropathy are not covered at all. 12 years since my first chemo and I still have quite painful neuropathy in my fingers. My sister finished chemo and radiotherapy in February and has lost all feeling in her foot and is effectively very disabled now. She has been told her foot may never recover. No one told us about this.”

- Macmillan’s “Hidden at Home Report” confirms the above findings:
 - Around two in three people living with cancer have practical or personal support needs, and four in five have emotional support needs. These include needs related to mobility (e.g. getting in and out of bed, leaving the house), practical tasks (e.g. preparing and cooking food, housework, grocery shopping) and personal care (e.g. washing and dressing themselves, going to the toilet), among many others.
 - Overall, almost one in three people with cancer have practical or personal needs but do not get enough support or get no support at all. Almost half of people with cancer have emotional needs but do not get enough support or get no support at all.
 - One in five people with cancer experience a negative impact on their lives as a result of a lack of support for their personal or practical needs. In 2015 this was at least 380,000 people with cancer in the UK.

One in 14 people with cancer are constantly or often unable to wash themselves, dress or go to the toilet because of a lack of support. One in 10 are constantly or often housebound as a result of a lack of support. One in 13 are constantly or often unable to look after their dependents, such as children or other relatives.

- Six in 10 people caring for someone with cancer experience some kind of impact on their lives and few receive a formal Carer's Assessment.
- The Communities Against Cancer patient events show the third biggest area of concern for patients is around post diagnosis support and what happens after treatment for cancer.
- Feedback about End of Life services and experiences includes:
 - Patients and families want to be prepared, have good plans in place, to be informed and to know what support is available where and when. They want honest and easy communication and to be in control.
 - Families feel more support is needed for bereavement, for example the practical considerations such as returning to work and caring for family and younger people.
 - At End of Life people want tailored and individual care and support rather than having to “fit in” with local procedures. Feedback for hospice care is, in the majority, positive with a few comments about the need for more flexibility to cater for personal requirements and preferences.
 - Some BAME groups have a strong reliance on spiritual belief and practice, which may be important for end of life care.

e) Specific feedback from seldom heard communities

The following is important information in relation to certain groups who are disadvantaged in their access to engagement opportunities and cancer services. We have kept it separately because we feel it needs specific consideration in addition to the information already included in the themed categories.

- Seldom heard communities engage better when time has been taken to build a relationship and trust, especially for engagement and awareness activities. See other comments under Screening and Prevention section.
- The annual NCPES shows that BAME people are less likely to give feedback about treatment and when they do, they report a poorer experience of cancer care compared to white British patients. It was found through BAME focus groups that the security of personal information and cynicism about whether feedback will make a difference are among the key factors causing lower responses among BAME communities.
- Asylum seekers and refugees say they are often not taken seriously by health professionals and appointments are difficult to access especially with language barriers and the cost of telephone calls etc. Access to translators can take time and often people do not want to discuss personal issues with a total stranger who is not a health professional.
- The following are experiences of BAME people with cancer, collated through Macmillan. Some of the information included below will already have been referred to in previous sections but in order to reiterate and emphasise the issues arising for BAME communities we have repeated the information as documented in the original report:

- Cancer awareness and help-seeking behaviours among people from BAME groups are low across all ethnic groups.
- British South Asian patients reported significantly higher rates of symptoms associated with depression compared with White British patients following a cancer diagnosis (35.1% against 16.8%).
- The lack of conversations about cancers in certain BAME communities has had an adverse effect on their likelihood of engaging in cancer screening practices. (see Prevention & Screening section).
- Many of the BAME participants felt that they had been unable to discuss anything beyond their immediate physical needs with their GPs and hospital doctors. They reported that doctors often did not look at them in the eyes, listen to their concerns and worries, or answer their questions.
- There was a large discrepancy between what participants reported as their desired level of involvement and their actual level of involvement. This corresponds with NCPES findings that BAME patients are significantly less likely than their White British counterparts to report being ‘involved as much as they wanted in decisions about care and treatment’. There was a strong theme of wanting to restore some sense of control at a time of great vulnerability.
- Support groups are an integral component of cancer care. However, evidence suggests that this component is one in which BAME people living with cancer - or caring for someone who is - are less likely to access than their White British counterparts. Within the sample, this

pattern seemed to be caused in part by the limited supply of, awareness of, and demand for tailored BAME cancer support. It did not reflect lack of need. Some of the BAME participants and their carers actively sought support but did not find services that met their needs.

- For most BAME participants (regardless of their demographic profile), the end of treatment is often the point where the support needs may seem greatest. This is partly because these needs are the most unexpected (by patients, carers, employers and the wider community) and therefore they are the least catered for. In fact, the participants said they did not really have time to take stock of the full impact of their cancer until their medical treatment had ended. The reason for this was that until then, they had been intensely dealing with coming to terms with their diagnosis, making practical arrangements during treatments, and focusing on their most pressing physical needs.
- Evidence regarding ethnicity and uptake of follow-up surveillance found that cancer survivors from white communities were more likely to receive follow-up than survivors from BAME communities.
- The BAME participants had poor experiences at the end of their treatment and were less likely to receive treatment summaries.
- They were less likely to have had an in-depth discussion about their needs and the support that was available to them on discharge. They were less likely to have been advised about the signs and symptoms to look out for. They were also less likely to have received regular specialist follow-ups and to have been helped with the long-term physical and emotional impact of cancer and its treatments.

- Poor communication between healthcare professionals and the patient is often reported by BAME communities in end of life care.
- The research did not systematically explore whether the BAME participants with cancer had access to a Clinical Nurse Specialist (CNS). Very few spontaneously mentioned that they had access to a CNS but, for those who did, this was a key driver of satisfaction with cancer services. In particular it seemed to help with navigation across the NHS, with answering questions and with accessing additional services.
- Those participants living with cancer generally wanted less technical, more personalised information, presented proactively. More specifically, they wanted to understand their diagnosis and prognosis (including why they got cancer, and some explicit reassurance that cancer is not always a death sentence).
- They wanted clear, but simple, information on their treatment options and the associated consequences, both in the short term and the long term. This included information on the side effects of treatments (e.g., fatigue, hair loss, weight loss or weight gain). It also included practical information on how to cope with the impact of cancer and cancer treatment (e.g., contact details of key staff, relevant websites, financial help, community transport, maps of parking at hospitals, access to suitable wigs, dietary advice, recommended physical activities, alternative therapies, massages, access to counselling, etc.).
- BAME people are less likely to participate in clinical cancer trials. Some of the barriers to participation include cultural factors such as fear and cancer stigma, and mistrust of the medical system.

- BAME participants reported a lack of ease, ability or willingness to discuss their cancer with others due to the existence of stigma about cancer in their community. They told of how they were met with unsympathetic responses when they disclosed their condition.
- The BAME participants living with and affected by cancer were deeply concerned about minimising the negative impact of their cancer on loved ones. They did not consider their family members as ‘carers’ (the word is associated with paid employment, not love and care freely given by family members). They would therefore not request support for ‘carers’, but they were extremely worried about the additional burden of care that their cancer imposed on their loved ones.
- BAME communities are much less aware than other groups about various aspects of cancer. These include what cancer is, the warning signs of cancer, the lifestyle factors that increase or reduce the risk of cancer, and of the importance of early detection and screening.
- At the point of diagnosis, participants were more likely to report that they thought they would die and that there was little medicine could do to prevent this. They preferred not to use the word ‘cancer’ themselves, and reported significant difficulties in communicating their diagnosis to others.
- Macmillan also collated experiences of Bengali patients. People relied on relatives to translate for them, so miss out of vital information. Getting information in their own language was deemed to be very important but difficult to access. Relatives have to break the news to loved ones that they have cancer when this would normally be done by medical staff.

- How information is translated needs to be considered. Macmillan showed Bengali women a leaflet on symptoms of ovarian cancer and feedback was some words had not translated clearly. An example of this was ‘lower stomach and back’. In English this means the ‘lower back’, but in the Bengali version it is not clear which part of the back as there are different words for different parts of the back. The women explained that written Bengali is different to spoken Bengali. They felt some of the language in the leaflet is not ‘easy’ Bengali. For example, they explained that there are many different words for ‘breast’ and the one chosen will not be easily understood. Likewise the word used for ‘ovaries’ is not an easy word. It seems that the terminology used in the leaflet will not be the words that people are familiar with in this context.
- Information on travel costs is not consistent for Isle of Wight (IOW) patients. Some people have put off going for treatment on the mainland due to costs. Initial consultations may be on the island but people reported having to go to the mainland for tests and operations. “It’s “upsetting” and “embarrassing” to go on the ferry when you are being ill or with wounds etc.”
- People at IOW prison may not have the same access to screening and other appointments due to travel to the mainland and the lack of availability of prison staff to accompany them.

5. Conclusion

This report is a first attempt at pulling together and drawing themes about people's experiences of and engagement around cancer from across Dorset, Hampshire and the Isle of Wight. National and local information were used to create a 'starter' document setting out what we currently know about people's thoughts and feelings around cancer screening, early detection, treatment, care and beyond.

Whilst we searched intensively for reports, we recognise that our conclusions are based on the information that was available within the timescales of the project; and we know there is much more that could have been shared and reviewed. We think there is a real opportunity to look at how the system can better share and use its experiences and engagement intelligence to inform future cancer services.

There appear to be gaps or limited intelligence around, e.g., people's engagement in preventing cancer or End of Life care for cancer patients. With more time it would have been possible to look for learning from other parts of the system e.g. around prevention or End of Life services, so it may be exploring these further.

Seldom heard communities are yet to be involved in developing local services so there needs to be a real focus on this. There are opportunities to do this through Alliance partners, the Communities Against Cancer project and voluntary sector.

We are aware there is a lot of work going on to improve local cancer services, so we hope this existing feedback will be used to inform the WCA workstreams, so people are not asked the same questions over again and they know their feedback is valued and acted upon. We hope that this information will be built on, with a strong commitment from the WCA and its partners to continue meaningful involvement and coproduction across all areas of its work remains person-centred.

6. Recommendations

We would like to make the following recommendations to the Wessex Cancer Alliance from undertaking this literature review:

1. Review the findings of this report and use it to inform the WCA's response to the NHS Long Term Plan and its future workstreams.
2. Consider whether the following gaps in intelligence should be explored further:
 - People's engagement in preventing ill-health, particularly from communities and groups who experience the worst health outcomes
 - People's understanding of genomics and the impact this will have on their treatment
 - End of life care for cancer patients and their carers / supporters
3. Improve how experience and engagement intelligence and good practice is collated and shared to enable Wessex Cancer Alliance partners to access this easily to influence future service improvement and minimise duplication (see specific recommendations on page 6).
4. Commit to meaningful coproduction with patients, carers and the public, particularly with those who are seldom heard and experience worse outcomes, in all the future workstreams.
5. Implement more effective equality monitoring and use of demographic data for engagement and experience activities. Both these recommendations will enable service design and improvement to take appropriate account of differences.

Appendix A: Methodology

We asked all local cancer service commissioners and providers, including the voluntary sector, to provide us with their recent (2 to 3 years old) service user/carer experience and engagement reports or information. We also researched websites, interrogated the Patient Experience Library and spoke to commissioners and providers. The full list of the 131 documents we reviewed can be requested. Whilst we pulled together what we could in a short timeframe, we are aware that we received a very limited amount of local intelligence² and there will be gaps in the information we present. For example, only three Foundation Trusts were able to respond (with information on a limited scale). To supplement this, we used high level data from the recent National Cancer Patient Experience Survey (NCPES) and the local Healthwatch Long Term Plan survey results, but although covers patient experiences from those Trusts, does not go into detail. Analysis of the free text comments could be undertaken at Trust level but unfortunately we did not access to this.

Even though we were unable to access information from most of the Foundation Trusts, we are aware that they do hold further useful information that may be relevant. For example, Portsmouth advised that they created a mini questionnaire, developed with their Patient Experience Team, that allowed them to explore some of the reasons behind their results of the NCPES survey. Poole advised that they also do further work with the Dorset Cancer Partnership patient engagement group.

² IOWFT “Cancer Patient Experiences Exercise” (Doc 3); Dorset CCG “EQIA Dorset Macmillan Cancer Information Service (Doc 4); Hampshire Hospitals “feedback from various awareness events” (Docs 5 to 9); Weldmar Hospice “Patient experience questionnaire” (Doc 10); WCA “Show Cancer the Red Card” (Doc 13); WCN “Social Capital Workshops” (Docs 14 to 17); HW IOW “2 reports on cancer services for IOW residents” (Doc 19 & 20); Action Hampshire “Older Peoples Experiences of Healthcare in Mid Hampshire” (Doc 23); The Living Tree “Chairs Report” (Doc 28); Phyllis Tucker Hospice “End of Life Care Engagement Report” (Doc 29); DCHFT “Haematology report” and 2 reports on carers and patients views of lung cancer services (Docs 32,33 & 35); West Hamps CCG “feedback from breast cancer patients” (Doc 36); WCA “Stakeholder Engagement Report” (Doc 37); Hampshire Hospitals “Networking event for cancer support groups and organisations in North Hampshire” (Doc 40); HW Hampshire “3 cancer case studies” (Doc 42); WV “Cervical screening & Easter European Women” (Doc 60); WV “Why Don’t Women Go” (Doc 61); WV “Patients experiences of exercise - WESTFIT pilot” (Doc 62); Macmillan & NHS Dorset Cancer Partnership “Dorset Macmillan Cancer Information Project Engagement Report” (Doc 64); “Early detection of lung cancer in patients with COPD” (Doc 70)

The only information that covered experiences from local Black, Asian and minority ethnic (BAME) communities and those from seldom heard communities was from engagement activity undertaken by Wessex Voices around screening. Equality monitoring information in reports was also generally limited, and usually only captured age and gender, not the other protected characteristics.

We recognise that this is an initial attempt at gathering information from a wide range of different sources and that there will be other information in existence. If other information is available, we recommend sharing it across the system and reflecting on whether it changes the nature of the findings in this report.

Like another recent literature review we have recently undertaken across [Hampshire and the Isle of Wight around Mental Health](#) the exercise of finding and accessing this information itself highlighted some learning, from which we make some specific recommendations.

Learning from this process

- Apart from the Patient Experience Library and, to a lesser extent, via Healthwatch England, there is no “central repository” for experience and engagement information so it is time consuming and resource intensive to source and gather existing feedback from services across Wessex and nationally.
- Very often information in patient engagement and involvement reports is general feedback and not cancer specific (or any other condition specific). It is therefore almost impossible to extrapolate cancer specific information from most reports. This includes information relating to the Friends and Family Test (however we make an assumption that within individual Trusts the FFT data

can be drilled down for specific areas and free text comments are analysed). Much relevant and useful service specific feedback will be lost due to this.

- We also found that the information gleaned from national data is very often site specific (in terms of geographical location or service) so may not be relevant to the whole of Wessex. Unless the service being commented on is provided in the same way it may be difficult to compare. Wherever possible we have used national data that appears to be more generic in nature. We found there are potential rich sources of data that are not publically available, for example surveys and focus groups undertaken and actioned at “local level” in wards, units and services that may not be shared centrally even within the same organisation. It is therefore not clear if this information is being used to influence decision making at higher levels within organisations.
- The degree and quality of the information and the reporting of service user experience, varies widely. **Macmillan reports are an example of good practice. Easy to find, read, understand and have useful summaries of the feedback received.**
- It has not been easy to generalise comments for this review due to the scope i.e. all cancers. As we know a patient with a brain tumour will have a very different experience and pathway from a patient with cervical cancer and so on.

Recommendations

It would be impossible for all organisations in the NHS, social care and the voluntary sector to produce reports in exactly the same format. It should, however, be possible for NHS colleagues undertaking engagement and experience activities to have consistent standards on ensuring publicly available information is more accessible, both for readability and transparency, by:

- Producing short, clear summaries of the report findings and recommendations.
- Clearly labelling and dating reports with relevant, user-friendly titles and publishing them on organisations' websites under 'involvement' or 'experience' sections.
- The above would make it much easier to create a public, searchable central repository for such reports (across all services), or to utilise an existing tool, like the Patient Experience Library.
- Make better use of demographic data when reporting on general feedback, where possible, and to link the feedback with the patient condition/disease.
- Getting involved in discussions with other Alliances that are developing interactive and digital innovations to make better use of the NCPES data.

Appendix B: Useful information and resources for engagement

- Health and wellbeing events seem to be most useful pre (after diagnosis) or post treatment. Feedback suggests information on diet and nutrition is most requested.
- Use of model inflatable body parts for awareness events are a big draw and generate interest from people and start conversations and engagements.
- Local knowledge is vital when undertaking engagement as is liaison with other stakeholders and communities to understand the best time and place for engagement work. Community representatives understand how to reach people and work with them, building on social connections and resources. Community leaders can also identify people to act as interpreters when needed, which is often cheaper, quicker and the people know and trust them.
- Pop Up shops, screening parties, taxi companies (promoting awareness), partnering with charities, volunteering organisations, Universities, Colleges (e.g. University of Southampton Lifefab) and schools were all cited as proven ways to engage.
- Visiting a Polish mother and toddler group to gain feedback about cervical screening and why eastern European women don't attend screening generated a far better response than a broadbrush approach.
- The Communities Against Cancer project is supporting seldom heard communities to undertake activities around screening and early diagnosis in a way that meets their needs.

Appendix C: Results from the 2017 National Cancer Patient Experience Survey

Note - 2018 data was not available at time of writing

In addition to the information gleaned from the literature review we have included some of the high level analysis from the 2017 NCPES, both nationally and then locally. The freetext comments from the survey are not publically available to include in this report. Scores for patients not having care plans and scores relating to questions around information and communication are interesting when compared to the feedback analysed from the literature review.

- Results from the 2017 NCPES show overall rating of care has gone up. Men have a higher rating of satisfaction than women with the biggest difference being in the perception of how much care and support patients were given from health or social services once cancer treatment was finished. 48% of men reported a positive experience compared to 42% of women.
- People who describe themselves as “white” have a generally more positive experience of cancer care than people who describe themselves as being non-white ethnicity. The largest variation being in the perception of how much care and support patients were given from health or social services once cancer treatment was finished - white people reporting 46% satisfaction and black people reporting 31% satisfaction.
- Younger people are likely to have a lower rate of satisfaction than older people particularly with their understanding of explanations of their illness. 77% of patients aged 75-85 years were happy with the explanation of their illness compared with only 60% of 16-24 yr. olds.

- Across tumour groups, patients with brain tumours are likely to experience the lowest satisfaction levels, whilst those with melanoma are likely to report the highest. The only area nationally to show a significant deterioration since the last survey was in the level of support patients experienced from GPs and nurses at their general practice. In 2017 60% thought that their GP did everything they could to support them while they were having cancer treatment which was significantly lower than the previous year's score of 62%.
- 91% of respondents said that they were given the name of a Clinical Nurse Specialist who would support them through their treatment. And 86% said that it had been 'quite easy' or 'very easy' to contact their CNS.
- 89% of respondents said that they were treated with respect and dignity in hospital, and 79% said they were definitely involved as much as they wanted to be in decisions about their care and treatment.
- Patient Experience Library's review of NCPES and the Adult Inpatient Survey adds:
 - 25% of patients thought their family (or someone else close to them) were not given all the information they needed to care for them after leaving hospital. In the NCPES, only 59% of respondents said that the doctors or nurses definitely gave their family or someone close to them all the information they needed to help care for them at home.
 - Additionally, less than two-thirds of patients (62%) left hospital with written information telling them how to look after themselves post discharge. Patients were asked if they had a written care plan but found only one third (35%) said they had been given one.

- Since NHS strategies stress the importance of “self-management” for people with long term conditions (including living with and beyond cancer) the issue of information giving is crucial. Differences in the way questions are asked may mean that the Cancer Patient Experience Survey and Adult Inpatient Survey are not directly comparable. But the similarities are striking, and taken together, the surveys seem to be pointing to an area that suggests room for improvement.

Summary of Wessex area results from the 2017 NCPES survey:

- 89% gave an average rating when asked to rate care on a scale of 0 to 10 (10 being high).
- 79% said they were definitely involved as much as they wanted to be in decisions about care and treatment.
- 91% said they were given the name of their CNS who would support them through treatment.
- 88% said it had been “quite easy” or “very easy” to contact their CNS.
- 89% said overall they were always treated with dignity and respect while in hospital.
- 95% said hospital staff told them who to contact if worried about their condition or treatment after they left hospital.
- 60% said they thought GPs and nurses definitely did everything they could to support them while they were having cancer treatment.

Areas outside expected range (lower in red, higher in green):

Overall NHS Care:

- Patient given a care plan 31% (average 35%)
- Overall administration of care very good 91% (average 90%)

Seeing Your GP:

- Patient thought they were seen as soon as necessary 85% (average 84%)

Diagnostic Tests:

- Length of time waiting for tests was about right 89% (average 88%)

Finding out what was wrong:

- Patient given easy to understand written information about the type of cancer 71% (average 73%)

Deciding best treatment:

- Patient given practical advice and support in dealing with side effects of treatment 68% (average 67%). Statistically significantly better than 2016 at 65%

CNS:

- Patient found it easy to contact CNS 88% (average 86%)

Support for people with cancer:

- Hospital staff gave information about the impact of cancer could have on day to day activities 83% (average 82%). Statistically significantly better than 2016 at 81%
- Hospital staff gave information on getting financial help 59% (average 58%). Statistically significantly better than 2016 at 50%
- Hospital staff told patients they could get free prescriptions 83% (average 81%). Statistically significantly better than 2016 at 78%

Operations:

- Staff explained how the operations had gone in understandable way 77% (average 79%)

Hospital care as an Inpatient:

- Patient had confidence and trust in all doctors treating them 87% (av. 85%)
- Groups of doctors or nurses did not talk in front of the patient as if they were not there 85% (av. 82%)
- Patients' family or someone close definitely had the opportunity to talk to a doctor 75% (av. 73%)
- There were always/nearly always enough nurses on duty 68% (av. 66%)
- All staff asked patient what name they preferred to be called by 71% (av. 69%)
- Always enough privacy when discussing condition/treatment 84% (av. 86%)
- Patient able to discuss worries or fears with staff 56% (av. 53%)

Hospital care as a day patient:

- Patient able to discuss worries or fears with staff 73% (average 71%)

Home care and support:

- Hospital staff gave family/someone close all the information they needed to help with care at home 61% (average 59%)
- Patient definitely given enough support from health or social care during treatment 55% (average 53%)
- Patient definitely given enough support from health or social care after treatment 45% (average 45%) - same but this is very low

Overall NHS care:

- Hospital and community staff always worked well together 64% (average 62%)
- Patient given a care plan 31% (average 35%)
- Overall admin of care very good or good 91% (average 90%). Statistically significantly better than 2016 at 89%
- Length of time for attending clinics and appointments was right 72% (average 69%). Statistically significantly better than 2016 at 69%
- Taking part in cancer research was discussed with patient 32% (average 31%). Statistically significantly better than 2016 at 27%

Summary:

- Hospital staff giving information on financial help seems much lower for head and neck, prostate and urological cancers (Similar national results)
- Head and neck is lower for hospital care as an inpatient
- Patient able to discuss worries or fears with staff is all 60% or below - although still within average range this would seem to be low.
- Hospital care as a day patient - for haematology 46% (average 60%) - for patient given understandable information about whether radiotherapy was working. Head and neck also 42% (average 58%)
- Home care and support - in general is good across all cancers - although it's not good nationally either - especially for "patient definitely given enough support after treatment"
- Patient given care plan - low in general (22% for head and neck - 35% is average), breast 29% (average 38%) and Upper Gastro 29% (34% average)
- Patient definitely involved in decisions about care and treatment -
 - National 78.5%
 - RBCH 82.3% - significantly higher
- Patient found it easy to contact CNS
 - National 86.3%
 - DCH 93.5%
 - Hampshire Hosp 91.1%
 - Poole 90.7%
- Staff told patient who to contact if worried post discharge
 - National 94.2%
 - IOW 87.9%
- Patient average rating of care scored
 - National 8.8
 - NHS SE Hamp CCG 8.97
 - NHS Dorset CCG 8.92
- Patient found it easy to contact CNS
 - National 86.3%
 - NHS Dorset CCG 90.4%
 - NHS Portsmouth CCG 79.4%
- Staff told patient who to contact if worried post discharge
 - National 94.2%
 - NHS Fareham & Gosport 88.7%
 - IOW CCG 88.1%

Acknowledgements

Wessex Voices would like to thank all the people and organisations who provided us with information or spoke to us as part of our research for this report.

We would like to thank Miles Sibley of the Patient Experience Library for his help and providing us with access to their library of reports.

We would like to say a particular thank you to Annie Dimmick who undertook the significant task of gathering, reviewing and analysing all the information and then writing it all up in a short space of time.

Contact us

For more information about this report or our findings please contact:

Sue Newell, Wessex Voices Project Manager on Sue.Newell@helpandcare.org.uk or 07595 424198.