



Cancer Personalised Care and Support

Di Riley
Citizen Ambassador Healthwatch Surrey



The [NHS Long Term Plan for Cancer](#) states that –

“by 2021, where appropriate, every person diagnosed with cancer will have access to personalised care, including needs assessment, a care plan and health and wellbeing information and support.”

Significant progress has already been made on this front with Cancer Alliances, Integrated Care Systems (ICS), trusts and GP practices working together to offer personalised care interventions.



Cancer Personalised Care and Support

Project Purpose and Aims:

The aim was to understand what the experience of patients, carers and family members has been like, and to investigate what Personalised Care and Support Services they have found beneficial or may be missing during different stages of the cancer pathway.

- The data collection method was semi-structured interviews chosen as it allowed themes to be explored in-depth while also allowing for participants to raise new themes and ideas
- Interviews were carried out by the Citizen Ambassador for Cancer from Healthwatch Surrey
- The size of the study was limited by the number of participants who agreed to take part

Demographics of those interviewed

Diagnosis	
Bowel	1
Head and Neck	1
Melanoma	1
Prostate	2

Type and Route of Referral/Treatment
1. NHS to Private Practice
2. Private Practice to NHS
3. Screening to NHS
4. GP to NHS
5. Acute Care (NHS) to NHS

Year of diagnosis	
2017	1
2020	2
2021	2

Stage of disease	
Local	2
Regional	2
Advanced	1

Gender	
Male	3
Female	2

Age	
Average age	64.5
Median age	64

Findings: aligned to Macmillan 5 core components



1. Everyone diagnosed with cancer has a supportive conversation

- Variation in the level of interpretation of what a 'Supportive Conversation' is, apart from one participant (predominately treated privately), none felt fully supported.
- One participant felt their Cancer Nurse specialist (CNS) never had time for him, and he was 'in a system'.
- Another commented on the number of times they had to repeat their past medical history or medications prescribed, which raised concerns about communication and continuity between the different clinical teams.
- There were also comments about not feeling able to talk openly, the processes happening too fast along with not fully understanding exactly what the treatment entailed or how they might feel afterwards.

'I felt cared for, not cared about'



Findings: aligned to Macmillan 5 core components



2. Health and wellbeing information resources are made available during the conversation and throughout a person's cancer journey

- This varied between participants, some were told not to look on the internet, whereas others felt they were given lots of leaflets but did not really get advice on which to look at when.

'I was told not to look on the internet for information'

'Family felt they had to do 'all the running & chasing' to get help, support and advice

3. The person's needs are assessed in line with a Holistic Needs Assessment (HNA) approach

- None of the participants were asked to complete a 'concerns checklist or other similar assessment tool to enable their clinical team to understand their holistic needs
- Similarly, the majority felt there was no attention to their emotional wellbeing

'No attention was paid to my emotional wellbeing'

'...never really felt that experience was personal and aimed specifically for him – it felt like being in 'the system', everyone was very nice, but he always felt they were busy, and his questions would be trivial'

Findings (Cont'd)

4. A personalised care and support plan, facilitated by their assessment, is developed with the person living with cancer

- None of the participants were given a personalised care and support plan by their hospital clinical teams
- There was mixed support from Primary Care provided for the participants, which varied from good support to 'hopeless'

'I felt my care was definitely personal and specific to me'

'My clinical team was 'amazed' when I told them I struggling emotionally'

'I felt I was taking up valuable time of the clinical team'

'We were not included in the development or discussion of treatment plans'

'My wife & I felt that we did not get any emotional or holistic support from our clinical team. We never felt we could talk freely to them or the CNS about personal issues that were worrying us'.

Findings (Cont'd)

5. Every person with cancer can access help by navigating the care and support they need

- There were mixed views to this core component, which probably reflects the differing needs of the participants to be in control of their condition.
- One participant felt they wanted to locate chat rooms and helplines themselves whereas others felt they did not get any help with signposting local support groups.

‘It all felt very impersonal, I work in health care and was getting lost in the system which I was supposed to know!’

‘I felt invisible, no one told me what was going on, I felt very frightened.....vulnerable and alone’’

‘using on-line chat forums and self-help groups have been where I have found most support and information’

Recommendations

1. All clinical teams are asked to ensure every patient has a holistic needs assessment which is reviewed with the patient and their supporters
2. All clinical teams are asked to ensure every patient has a Personalised Care and Support Plan, which is shared with the patient
3. Clinical teams need to ensure that all patients have access to a Clinical Nurse Specialist (CNS) or other key worker who can coordinate care, respond to concerns, and generally support patients.



How to contact Healthwatch Surrey

Telephone: 0303 303 0023 (local rate number)

Text (SMS): 07592 787533

Email: enquiries@healthwatchsurrey.co.uk

Website: www.healthwatchsurrey.co.uk

 /HealthwatchSurrey

 @HW_Surrey

 healthwatch_surrey

 Healthwatch Surrey