

Peninsula Cancer Alliance Sleep Evaluation

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With thanks to:

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Carly Seller, Healing Sound and Energy Practitioner

Patrick Causely and Jess Wallbridge, Bath Spa University interns

The staff at The Mustard Tree Cancer Support Centre

Patients and carers who shared their experiences

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Background

It is well recognised that more people are surviving cancer than ever before and living with cancer, and the effects of its treatment can have a significant impact on peoples physical, emotional and social wellbeing. Understanding the impact of a cancer diagnosis on a person’s quality of life is essential to ensuring that treatment, support and services received by patients is appropriate and meets their needs.

In order to address this, NHS England launched the [Cancer Quality of Life Survey](#)¹ (CQOL) in September 2020. The aim of the survey was to provide an opportunity to share and highlight how a cancer diagnosis has impacted the patient and their families and to provide long term insight into the longer-term effects that cancer may have on a person’s quality of life, in order to guide service improvements that will better support those who had/ have cancer to live as long and as well as possible.

The survey is now being sent to cancer patients around 18 months after diagnosis and covers most tumour sites. Since its launch the Peninsula Cancer Alliance (PCA) has maintained an average response rate of >50% with 3586 males and 3596 females responding to the survey.²

¹ <https://www.cancerqol.england.nhs.uk/>

² https://nhsd-ndrs.shinyapps.io/qol_dashboard/ - data as of May 2024

As part of the Cancer Alliance 2022/2023 Operational Planning Objectives received from the NHS National Cancer team, the PCA was asked to identify a quality of life priority for local intervention from the recently launched [Cancer Data Dashboard](#)³ and to complete a mapping and development plan.

Although there are a number of areas that could be suitable for local intervention, when reviewing the survey, it became clear that difficulty sleeping was a symptom reported by all cancer types (25.1%) and the PCA agreed that this was an area that should be explored further as part of the above objective.

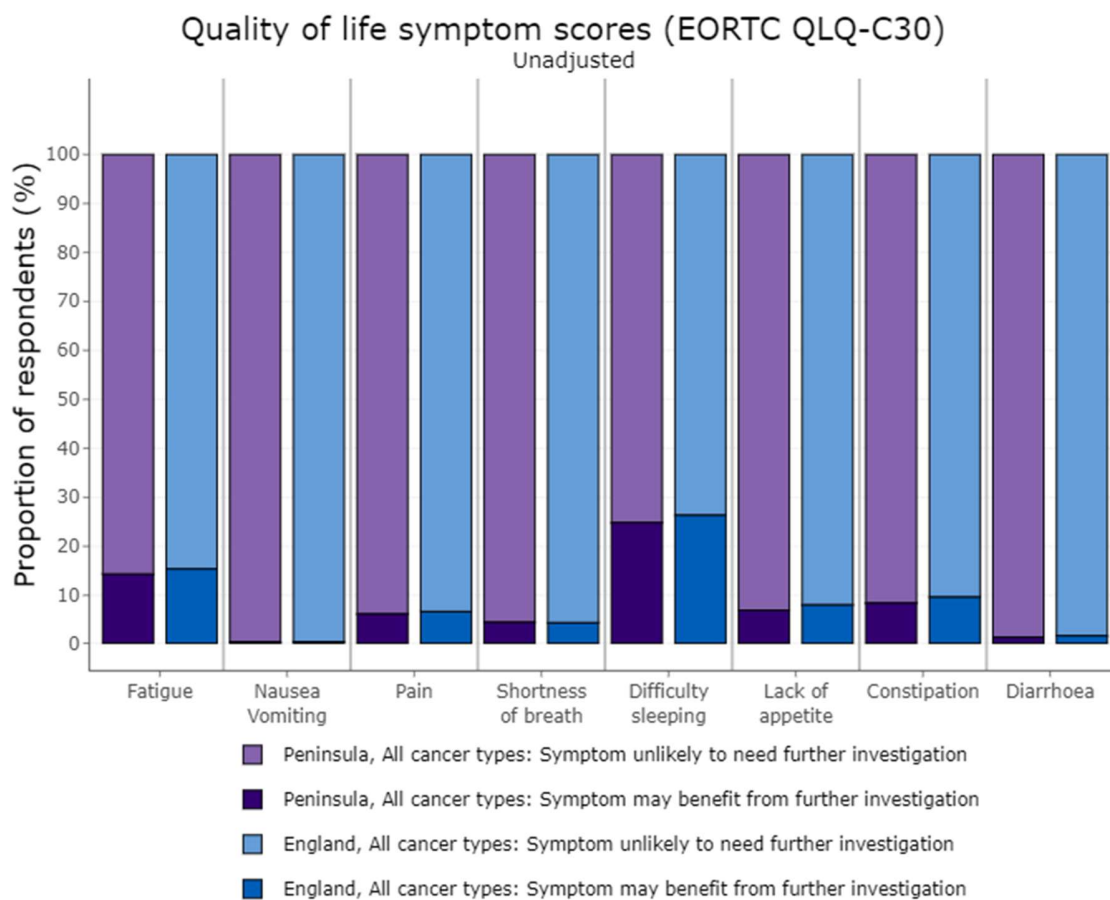


Fig. 1 Quality of Life Symptom Scores (EORTC QLQ-C30) – The chart shows the percentage of people who report each symptom at a level that might benefit from further investigation. Please note: May 2024 data.⁴

³ <https://digital.nhs.uk/ndrs/data/data-outputs/cancer-data-hub/cancer-quality-of-life-survey>

⁴ https://nhsd-ndrs.shinyapps.io/qol_dashboard/

Tumour Site	Peninsula %	National %
Breast	29.9	33.3
Colorectal	21.1	22.5
Gynaecological	28.3	28.4
Haematological	24.1	25.6
Head and Neck	27.2	26.1
Lung	29.5	32
Melanoma	19.2	18.5
Prostate	21.4	22.1
Upper Gastrointestinal	31.9	27
Urological	25.2	25.9
Other	22.7	23.5

Fig. 2 Percentage of patients who reported difficulty sleeping as the biggest symptom that might benefit from further investigation by tumour site. Difficulty sleeping is the highest reporting symptom in all tumour sites. Please note: May 2024 data

Methodology

We began to explore sleep difficulties further by completing a mapping exercise to capture what current support is offered to patients across the Devon and Cornwall region. [Please click here to view the completed mapping template.](#)

The following was identified from the mapping exercise:

- Patients with Sleep Aponia had access to specialist services within secondary care, however there was little to no free sleep service/ pathway for cancer patients across Devon and Cornwall struggling with sleep insomnia.
- A Devon TALKWORKS Improving Sleep Workshop course is available, but this does not include Plymouth and Cornwall patients. This is not a cancer specific course and is online only.
- All areas offered some form of complimentary therapies to cancer patients in order to help and manage stress and anxiety i.e. meditation, massage, although these services varied centre to centre.
- Basic sleep hygiene support was offered by nursing teams/ cancer support centres via health wellbeing information and support offerings.
- The [Sleepio App](#)⁵ is a free Macmillan funded app available for all cancer patients in England. Sleepio is a 6-week self-taught programme. Awareness of this App was very limited within services.
- Private clinics were available but at a cost.

⁵ <https://www.sleepio.com/sleepio/nhs/391#1/1>

The PCA was unable to identify any equitable free support for patients with sleep insomnia across any long-term health conditions.

Sleep Focus group

In order to explore patient experiences further, the PCA held a focus group in April 2023 and invited patients/carers from across Devon and Cornwall who had received a cancer diagnosis over the previous 2 years. [Please click here to view the focus group poster.](#)

6 patients joined this focus group which was held at Exeter Library and they were asked to detail their experiences with sleep, what they do to self-manage sleep issues, and what would have been useful for them when undergoing treatment and living with and beyond their cancer diagnosis. The Sleepio App was also demonstrated to the group. To note that all 6 patients were not familiar with the Sleepio App.

Key themes from the focus group were;

- Participants had accessed complimentary therapies via their Cancer Support Centre i.e. Reiki/ Mindfulness
- Anxiety overpowers sleep
- Treatment makes sleep particularly challenging i.e. fatigue, toxicities and side effects.
- Commented that it would be useful to have resources in one place. Liked the idea of a Sleep Toolkit using a QR code.
- Many of the participants were managing their sleep with medication (either anti-depressants or sleeping pills).
- Some participants had used the following to aid them with their sleep; BBC Radio/ White Noise machines/ sleep pillow spray.

Sleep Focus Group – April 2023

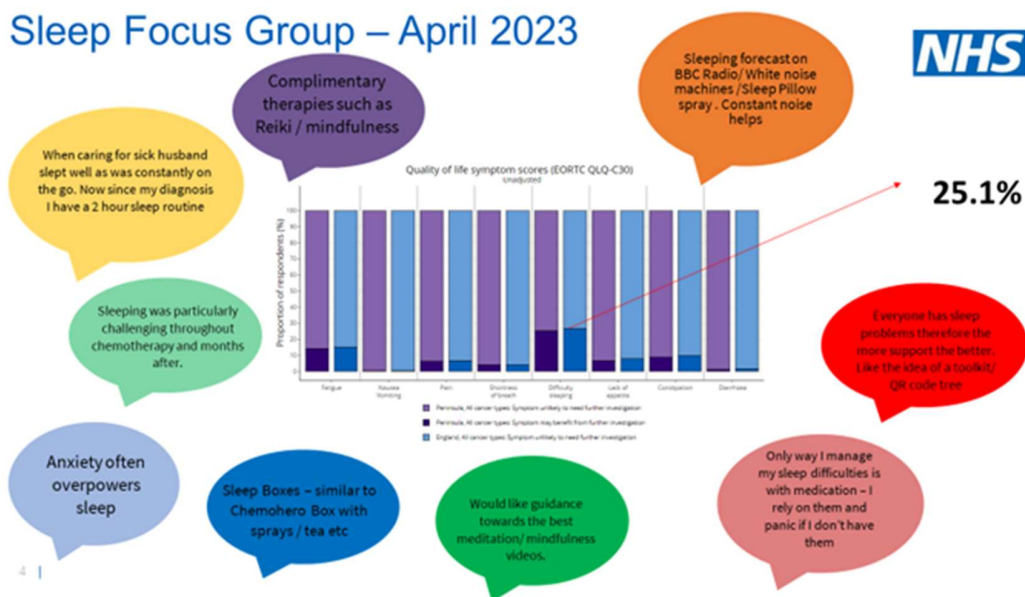


Fig.3 Experience captured from Sleep Focus Group

Bath Spa University Interns

In collaboration with Bath Spa University, the PCA has been able to offer and recruit two placement year posts to work within the Cancer Alliance.

The aim of these posts is to:

- Research, identify and create short video stories
- To aid the understanding of cancer services
- Help to demystify an experience many fear and to highlight the work of those who help.

The PCA Interns identified Sleep as a project that they would like to create content for, aimed at providing some meaningful tips to help patients who are having difficulty sleeping.

PCA Sleep Workshop in collaboration with The Mustard Tree

In March 2024 the PCA in collaboration with The Mustard Tree Cancer Support Centre hosted a Sleep Workshop Event for cancer patients across Devon and Cornwall. This workshop was offered in two repeat sessions morning and afternoon. [\(Please click here to view the poster for the event\).](#)

The aim of the event was to provide health wellbeing information and support to patients who have had difficulty sleeping by providing practical and meaningful tips. It was also an opportunity for the PCA to capture further experiences around this topic from those with a lived experience of cancer.

It was held at the Copthorne Hotel in the city centre of Plymouth conveniently located by the train and bus stations. The venue had space for networking stands for various charities and services i.e. Macmillan, Citizens Advice Bureau, South West Coast Path Walking Group and Local cancer support centres. Time was allocated within each of the two sessions to allow for the delegates to look around/ talk to the stands.

Key Note Speaker: The Sleepy Head Clinic – Stephanie Romiszewski, Sleep Physiologist

Stephanie Romiszewski specialises in insomnia and complex sleep disorders. The Sleepyhead clinic provides treatment for patients as well as working alongside the NHS to provide sleep education training for medical professionals.

Stephanie currently works at the Royal Devon University Hospitals NHS Foundation Trust (RDUH) under the occupational Health team. Stephanie feels that there is inequality of support to patients with long term health conditions who are struggling with sleep across Devon and Cornwall. Stephanie uses CBTi in order to help people change their behaviours around sleep.

About CBT-I

CBT-I focus is on restructuring of thoughts, feelings and behaviours that are contributing to insomnia, and techniques involving stimulus control, sleep restriction and relaxation training. Sessions often include cognitive behavioral and educational components and when used together a multicomponent CBT-I as many as 70-80% patients with primary insomnia experience improvements.⁶

Additional speakers

The following speakers also contributed to the event: [*\(Please click here to view the agenda for the event.\)*](#)

- David Jenkin, Personal Trainer and Exercise Rehabilitation Instructor. David has worked in exercise rehabilitation since 2010 specialising in oncology but in the past has worked extensively in cardiac care, osteoporosis, arthritis, lung conditions, pain conditions and much more. David delivered a talk on connecting physical activity to a better sleep quality and demonstrated a number of exercises to delegates who were able to also practice the exercises whilst sitting using their free exercise bands.
- Carly Seller, Healing Sound and Energy Practitioner. Carly offers sound meditations, yoga classes, Body Temple Dance practices and creative workshops to explore embodied expression. Carly provided mats for each delegate and delivered a 30-minute sound bath session to end the event.
- Rosemary Martin, Registered Dietician. Rosemary currently works at the Royal Devon University Healthcare Foundation Trust within the occupational health team but has a

⁶ <https://www.sleepfoundation.org/insomnia/treatment/cognitive-behavioral-therapy-insomnia>

background of working within oncology. Rosemary's talk focused on how eating well can support a healthy night's sleep.

Jessica Wallbridge and Patrick Causley, the two Bath Spa University Interns filmed each speaker and were able to capture lived experience to support their Sleep Video project.

Cost of the event

Breakdown of costs for the event was as follows;

- Sleep Physiologist - £1000
- Exercise therapist- £400
- Dietician- £400
- Sound Bath - £400
- Venue hire £650 with tea/ coffee refreshments and including parking for attendees.
- Information leaflets detailing exercises and top tips for sleep were given to each delegate.
- Each delegate received an exercise band to take home
- Fruit bowls were at every table for delegate to eat/ take home

Advertising

The event was advertised across social media channels, key stakeholder groups and within local support centres across all of the Peninsula Cancer Alliance such as;

- All clinical network site specific groups
- PCA Personalised Care group
- Cancer operational group and Lead Cancer Nurses
- All 5 cancer support centres in the region - the centre staff actively encouraged patients to sign up to the event
- Primary care networks
- Other organisations/ charities such as Macmillan, MySunrise App
- The event was tweeted from the PCA account and also by other stakeholders.

Results and Event Feedback

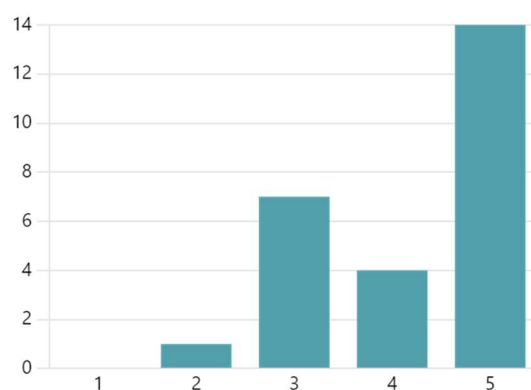
Feedback from the sleep event and key learnings

The PCA Sleep event (in collaboration with The Mustard tree) was attended by 61 patients and carers from across Devon and Cornwall. Due to the geographical challenges within Devon and Cornwall, the majority of attendees were from the Plymouth area but some did travel from Torbay, Exeter and Cornwall to the event. Throughout the event, attendees were given the opportunity to speak to various charities from across the region, i.e. Macmillan, Citizens Advice Bureau, South West Coast Path Walking Group and Local cancer support centers.

Following the event, a brief survey was sent to each attendee to capture their feedback, learnings and their experience with sleep. 27 responses to the survey were received.

The attendees were asked the following;

1. On a scale of 1-5 (5 being a lot) how much do you feel your sleep has been affected following your cancer diagnosis



4.19 Average rating (26 responses)

2. Please give a brief explanation of how you feel your sleep has been affected

14 respondents (54%) answered **Broken sleep** for this question.

healthcare prof difficulty sleep with the pain little sleep sleep deprivation sleep patterns night thoughts re lots broken sleep dry mouth intrusive thoughts Waking continuously asleep no pain steroid chemo treatment interrupted sleep Recently following day

Broken sleep

- Broken Sleep, Intrusive thoughts
- Broken sleep, getting up in the night to pee and not being able to get back to sleep, thoughts re a lot of things.
- Intrusive thoughts, depression, stress

- I've had broken sleep with the **pain** I've had
- **Pain** and intrusive thoughts difficult to fall asleep
- I have not slept properly for years, **I experience pain since my cancer**
- **Tired in day can't sleep at night**
- Broken sleep, intrusive thoughts, **pain, nausea**
- Waking up from as early as 4am onwards. How much is related to **steroid meds**?
- **Brain working overtime**
- **Night sweats** and **bad dreams**
- Mostly broken sleep waking up with very **dry mouth** a dozen times but do not get to sleep again
- Difficulty falling asleep. **Long term discomfort after operation.**
- **Steroids** taken for 4 days every chemo treatment disrupted sleep significantly. Waking continuously throughout the night and not able to fall back to sleep again. Recently following 6 nights of very little sleep suffered from severe sleep deprivation.
- Interrupted sleep due to cough
- **Reflux**

3. Have you been offered/ received any support with sleep since receiving your cancer diagnosis?

YES	9
NO	13
UNSURE	4

4. If yes, what support have you been offered/received?

- **Sleeping pills**
- This workshop
- Mustard Tree – offered this workshop
- **Antidepressants**
- **Medications** that don't work
- **Advice with medication** and **pillow support**
- **Sleeping pills from GP.** Currently on a chemo break because of sleep deprivation and thankfully The Mustard Tree recommended this workshop

5. Please provide any feedback you have from the workshop (for example, are there any tips or advice you feel would have been useful)

- Excellent speakers, so interesting and informative
- I felt I knew most the discussion after being a bad sleeper for a long time

- Lots of things from the nutritionist
- **Getting up at the same time every day. Enjoyed the sound bath. What not to do in the middle of the night i.e. snacking.**
- **Not eating 2-3 hours before bedtime**
- Lots of information about sleep which I didn't know. It was very helpful
- **I didn't feel there was any great understanding of pain, lack of energy, tiredness, itching, mental stress.** Many cancer sufferers suffer these and many don't. Many have strong chemicals administered and "take a pill!"
- All very useful and has **provided me with tangible strategies to improve my wellbeing and sleep. I found the simple exercises that could be done at home really helpful too.**
- The **physical activity reinforced my belief in exercise**, Stephanie was a great presenter and loved the myth busting. I'm less convinced on the efficacy of tryptophan foods but I'll try them. The meditation was nice.
- Felt psychologist was very helpful as well as the nutritionist. Was hoping to speak with the citizens advice about financial matters as this contributes to lack of sleep but there was no time allotted for this, I arrived early but there were issues with parking which took up any spare time.
- Speakers were very informative. **I liked how to not allow the thought of not sleeping can cause more of an issue and that our bodies will make up for it as it goes into a deficit.** Some good practical advice on diet and exercise too.
- **I am finding getting up the same time each day to be particularly helpful.**
- Found talk by Stephanie excellent. **Have implemented many of her suggestions. Getting up at same time then I go outside for 30 mins to get daylight. Been walking more.**

6. Any other feedback or comments on the event?

- Found it was very interesting, like to go to one of them (workshop) again
- Would like to attend again!
- One of the psychologist's tips was not snoozing in the day, but then the sound therapist had everyone laying down to relax (there was some snoring) so I felt these 2 things contradicted each other. I came away with good ideas to try from the exercise, psychologist & nutritionist though. In all found the day helpful.
- I really enjoyed the sleep therapist. She talked a lot of sense
- Feel very grateful of timing of event and finding a sleep expert like Stephanie as had not managed to find any one myself as seem very rare and most advice online not detailed enough
- Very informative and the last meditation session was really relaxing
- **I came away feeling there were options for me other than medication.**

When advertising the sleep event, many professionals contacted the team and asked to join the event, either to support patients or to provide support to themselves personally.

Following on from the workshop a further short survey was sent out 8 weeks later to the attendees to measure the impact of the workshop and to see if they have seen any improvements in their sleep. 14 responses were received.

1. Since attending the Sleep Workshop have you implemented /adopted any of the suggestions made at the event?

YES	12
NO	2

2. If yes, please detail what changes you have made?

- Not worrying about sleeping
- Relaxation
- Less concern about interrupted sleep. I wake up as often but as I don't get tired during the day I don't worry whether or not I get enough sleep because I feel as if I do.
- Preparation for sleep earlier. Using routines of time and habits to prepare for rest then sleep. Relaxation technique and adjusted diet.
- Getting out of bed the same time each day
- Going to bed at a consistent time
- Not eating 3 hours before bedtime, and not looking at my iPad in bed, and exercising
- Avoided food that it was suggested may affect sleep and I don't use my iPad before bed now
- Not worrying, trying to stick to wake up time
- Diet changes
- Prepare the bedroom early so ready to go to bed when tired
- Use of advice regarding times/ consistent wake up

3. Please detail any improvements/ differences that you have noticed with your sleep since you attended the Workshop below.

- Sleep better!
- I feel more relaxed and able to fall asleep better
- Little change just less worry
- No change
- Easier to rest now. Learning to apply strategies for wakeful nights using suggested methods of breathing and relaxing into it rather than fretting over periods of wakefulness
- Sleeping better through the night
- I'm sleeping all night. I might have the odd night feeling restless but not often

- Slightly more relaxed about waking up every night
- I seem to be able to get to sleep easier on some nights but still not all
- Still tired but feel better. Can go back to sleep better in the night instead of hours awake.
- Being more relaxed about it
- Some improvement seen

Challenges of the event

One of the main challenges with running the event was the time element involved in the organising and we relied heavily on the support of the staff within The Mustard tree. However, now that this workshop model has been developed it can be easily replicated for future events. The model of this workshop could also be replicated to cover other topics and to allow us to use insights from data to provide further workshops, for example, pain, fatigue, psychosocial.

Due to the geographical nature of the Peninsula it is not easy to find a suitably located venue to host Peninsula wide events and this model could be replicated in the northern part of Devon or further into Cornwall to reach more patients.

Conclusion and Recommendations

Key themes identified;

Although most people will experience insomnia at some point in their lives, a cancer diagnosis and living with and beyond a cancer can cause insomnia. Potential reasons for this include;

- symptoms caused by the cancer (such as pain and sickness)
- side effects of treatment
- worry, anxiety or depression⁷

Unsurprisingly, anxiety, intrusive thoughts, depression and pain were keen themes identified from the local PCA patient feedback and it is clear that more could be done to support patients to live well with cancer when it comes to improving quality of sleep.

The take away message shared by Stephanie at the sleep event advised that we need to normalise sleep changes. Please [click here](#) to view the support sheet from the Sleepyhead Clinic that was given to all delegates. Stephanie encourages her clients to try to avoid worrying about sleep and to concentrate on enjoying their day, (staying awake gives you the energy to sleep!) but she also provides some helpful tips to help strengthen sleep and offers advice on where to get help if insomnia becomes unmanageable.

⁷ <https://www.cancerresearchuk.org/about-cancer/coping/physically/difficulty-sleeping>

We know that following cancer treatment late effects are side effects that do not go away after cancer treatment and that they do not happen until months or years following treatment. This could be an area of focus for the Peninsula Cancer Alliance as we know late effects and rehabilitation services for people living with and beyond cancer can help to improve a person's quality of life. These services within the Peninsula vary and currently the late effect services are predominately focused around radiotherapy side effects.

Many patients reported that they used medication in order to manage their sleep insomnia. Could there be an opportunity here to provide professional training (CBT-I) to clinical teams, primarily within primary care but also as part of patient education offering? Further opportunities would be through the information and support delivered at health wellbeing events and end of treatment clinics? It may also be beneficial to look at top concerns reported from GP Cancer Care reviews to understand if sleep is a common concern reported.

Next steps

Discuss with the wider PCA team, Board and key stakeholders in the region to agree the next steps.

PCA could consider setting out a Peninsula wide improvement plan to include the following;

- Promotion of 2 x sleep videos filmed by the Bath Spa Interns across the Peninsula.
- Explore development of sleep toolkit via MySunrise App and the PCA website.
- Training opportunities for clinical teams within primary and secondary care to enable them to support and signpost patients early and to help patients identify coping strategies.
- Health and wellbeing training for professionals to support them with sleep insomnia. A number of professionals wished to attend the workshop to help with their own sleep difficulties.
- The Sleepio App is currently a free resource for all cancer patients and could be promoted more across the region.
- Opportunities to work with the wider personalised care agenda and other long-term conditions. There is no equitable sleep offering to patient within long term conditions in Devon and Cornwall.
- Further workshops and focus groups focusing on pain and side effects of treatment and Psycho-social support using the above structure to identify further interventions for the alliance within these areas.
- Explore Re: Sleep – a virtual sleep programme combining evidence based, validated methods that patients can access anytime.