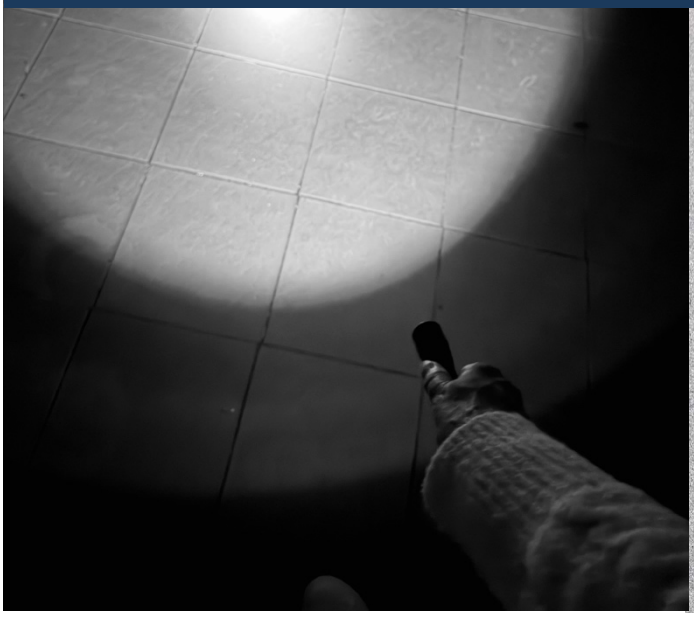
EXPLORING BARRIERS TO EXERCISE DURING CANCER TREATMENT

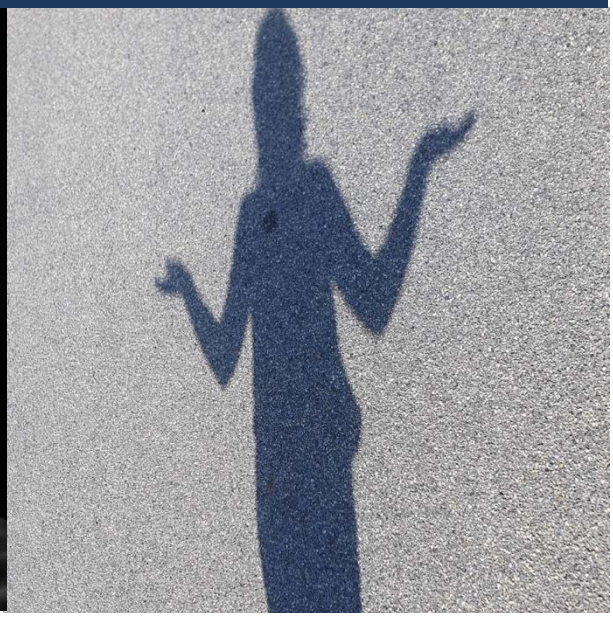
Photovoice and Micro Community Conversation

SUMMARY REPORT

"If it was given to us, we would do it."

Group 2: Non metropolitan: Peel & South West, Western Australia





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EXECUTIVE SUMMARY

"They're in the dark and they stay in the dark, which is really sad."

This report presents findings from the second Photovoice-informed Micro Community Conversation exploring barriers to accessing exercise during and after cancer treatment in Western Australia. It was delivered through a partnership between the Project SCENIC research team and the Consumer and Community Involvement (CCI) Program, and it centres the lived experience of six women, most of them living outside the Perth metropolitan area, who navigated exercise during breast cancer treatment between 2016 and 2025.

Participants photographed their experience over a four-week period, discussed each image in an individual interview, and then met as a group to look across the whole collection. What emerged was not a set of complaints about services, but a description of a system in which exercise is structurally absent. One participant relayed what her oncologist told her directly:

"It's not part of our treatment protocol or plan."

Every participant reported that exercise was mentioned to them briefly, vaguely or not at all. Where it was raised, it was raised once, in passing, by a single practitioner, and never again. One participant recalled the single occasion exercise came up during a year of treatment:

"That's the last time I heard exercise mentioned."

What the photographs showed

The most striking visual feature of this group's collection was **light and darkness**. Participants photographed blackness, torch beams, a lit page in an otherwise dark room, and light on water, to describe an absence of information that they experienced as a physical condition rather than an information gap.

"I was pretty much just kept in the dark about what I should be doing to help myself in regards to exercise and movement."

Care was shown **without exercise** in it. One participant built a jigsaw in which surgery, chemotherapy, radiation, scans, medication, physio, the breast care nurse and psychology all interlocked, while the exercise piece sat outside the puzzle altogether. Another photographed her daily plan during chemotherapy — chemo, nap, try to eat, nap, rest, sleep — a list on which movement does not appear. One participant photographed a page covered in the language of cancer — surgery, biopsy, isotope, lymphoedema, hormone therapy, reconstruction — with the word "exercise" written in small red pen, so faint that it was missed by the person she showed it to.

"Exercise is the missing piece, which connects all of those things."

"It is one small voice, in a cacophony of sound."

A fifth theme showed effort that returns people to where they started. Participants photographed a doll climbing and sliding back down a mound of dirt, a seat that circles a tree like a merry-go-round, a rope web, a rowing machine standing unused, and an unbroken white line on an empty road. These images described repeated attempts at self-navigation that ended in dead ends, at real financial and emotional cost.

"I'm climbing up a mountain and I'm almost at the top, and then I keep sliding back down."

What the conversations described

From the individual interviews and the group discussion. Participants were unanimous and emphatic that the problem was not motivation. Asked what would have changed things, the group's first and simplest answer was that exercise had to be given to them rather than suggested to them, and given safely:

"If it was given to us, we would do it. But it needs to be in a safe path."

Participants described contradictory messaging from inside the health system, including being told to rest by nursing staff immediately after chemotherapy, and conflicting instructions from surgeons, plastic surgeons and physiotherapists about what movement was permitted.

The burden of self-navigation was described as exhausting and expensive, and its cost fell unevenly. One participant had consulted eleven practitioners in twelve months, largely at her own expense, and had still not found appropriate support. Another had no income and could not join a gym. A third had private health insurance and named that as the reason she had done comparatively well.

"I think everyone has the right to have the same treatment."

Two participants described being given exercises by practitioners without cancer-specific training that caused pain or that they judged unsafe and declined to do. Participants located the problem in a workforce gap rather than in individual clinicians.

"They're just not able to understand how to help me because they don't have the training, so it's not her fault."

Distance, service scarcity and immune status shaped what was practically possible. One participant routinely drove a three-hour round trip for an eight-minute appointment and would have liked to exercise had a session been scheduled alongside it. Several described avoiding public gyms because of infection risk, and wanting small, cancer-specific groups instead. Local programs were valued but ran once or twice a year and could not be relied on.

Finally, participants argued for care that treats the whole person, and made an explicit economic case for doing so. They positioned exercise as part of remaining independent, staying out of the health system, and having a life worth surviving for.

"You're not treating the whole person. Where's the wellness treatment? There isn't any that exists."

Together, these findings show that the barrier is not awareness among consumers, nor willingness. Participants wanted to exercise, sought out information themselves, and did so while unwell, uncertain and unsupported. What was missing was a pathway: a named, trained practitioner attached to their care team from the point of diagnosis, a plan they were told to follow, and something safe and local to go to that was ongoing.

CONTENTS

ACKNOWLEDGEMENTS

Acknowledgement of Country

We acknowledges the Aboriginal people of the many traditional lands and language groups of Western Australia. We acknowledge the wisdom of Aboriginal Elders, both past and present, and pay respect to Aboriginal communities of today.

Acknowledgement of lived experience

We acknowledge the importance and expertise of the lived experience voice of health consumers and carers. We recognise their involvement in making a difference in supporting health research and impacting the health and wellbeing of our communities.

Acknowledgement of participants

This report belongs to the six women who took the photographs, sat for the interviews and joined the group conversation. Several described the process itself as valuable. One participant, who had spent more than a year trying and failing to find appropriate support, closed her interview by saying:

"I found my voice at last."

We are grateful for the time, candour and generosity of everyone involved, and for the work of the consumer members of the Project SCENIC team who facilitated the conversation and the individual interviews.

ABOUT THIS MICRO COMMUNITY CONVERSATION

Growing evidence demonstrates that exercise plays a critical role in improving physical function, treatment tolerance, mental wellbeing and quality of life during and after cancer treatment. Despite this, access to appropriate exercise support remains inconsistent, and exercise is not routinely embedded within standard cancer care pathways. Many people affected by cancer are left to navigate exercise information and services independently, often during periods of significant physical, emotional and cognitive burden.

The Clinical Oncology Society of Australia's position statement recommends that exercise be discussed, recommended and referred for every person diagnosed with cancer in Australia. The experiences described in this report indicate that this is not what is happening in practice, and that the gap between guideline and delivery is being absorbed by patients.

The Project SCENIC (Standardising Care for Exercise and Nutrition in Cancer) research program seeks to address these challenges by identifying ways to integrate evidence-based exercise and nutrition support more consistently within cancer care. Central to this approach is the recognition that lived experience is essential for understanding how care systems operate in practice, and where gaps and unintended consequences occur.

To inform this work, the Project SCENIC research team partnered with the WAHTN Consumer and Community Involvement Program (CCIProgram) to conduct participatory Micro Community Conversations (MCC) using photovoice methods. This report presents the second of these conversations. A group of six women (n = 6) with lived experience of breast cancer, drawn predominantly from the Peel and South West regions of Western Australia, shared photographs and narratives reflecting their experiences of accessing exercise during and after treatment.

Who took part

All six participants were women who had been treated for breast cancer. Their circumstances differed substantially, and those differences matter to the findings:

- Diagnoses spanned 2016 to 2025, so the group could speak to whether anything had changed over a decade. Participants concluded that very little had.
- Experiences ranged from early-stage disease treated without chemotherapy, through triple negative and stage 3 disease, to metastatic disease with extensive spinal involvement and no end point to treatment.
- Several participants had additional complications that shaped what movement was possible, including a fractured shoulder sustained during chemotherapy, cording, lymphoedema, spinal fractures and reconstruction that limited upper body movement.
- Financial circumstances varied widely. Some participants had private health insurance and used it extensively. Others had no income, were on a pension, or relied on community health services.
- Most participants lived outside metropolitan areas. One lived approximately three hours' round trip from her treating services. Several travelled regularly between regional homes and Perth hospitals.

Most participants were connected to a regional peer support group, which several identified as the only place they had ever heard exercise discussed. This is important: the most consistent source of exercise information described by this group was other people with cancer.

STRUCTURE & PROCESS

Part 1. Group discussion

Participants were introduced to the project in a face to face discussion with the consumer lead. She described the background and aims of the project, and how the process of photovoice and conversation would work together.

Part 2. Individual photography

Participants were invited to take photographs over a four-week period that reflected their experience of accessing exercise during and after cancer treatment. Guidance and example prompts were provided to support idea generation, and a consumer team member checked in during the period to offer support or clarification. Participants were encouraged to seek further assistance if they wished to brainstorm ideas or discuss their images. Completed photographs were submitted to the research team for collation.

Participants approached the brief in markedly different ways. Some photographed the landscape they walked in; others staged images, printing and cutting out a figure to place in a garden, writing words on paper, or arranging a jigsaw to represent their treatment plan. Several photographed themselves. Two used a doll as a stand-in for their own body. One photographed herself crying and asked for the image to be included.

Part 3. Photography discussion (individual interviews)

Each participant took part in a semi-structured individual interview with a consumer and research team member. Participants were invited to reflect on their selected images and discuss the meaning, context and personal experience represented in each photograph. Interviews explored how the images related to participants' experiences of accessing exercise during and after treatment, including perceived barriers, enablers and the broader impact on daily life and wellbeing. Open-ended prompts were used to encourage rich, participant-led discussion. Interviews also traced each participant's treatment history, so that the images could be understood in sequence — what was happening, and when, at the point each barrier was encountered.

Part 4. Micro Community Conversation (group discussion)

The group came together to view the full collection of photographs. Each participant spoke to her own images, with a consumer facilitator presenting on behalf of those unable to attend. The group then viewed the images generated by the first photovoice cohort, before being asked three structured questions about what the material meant collectively, what they would say to a funder or policymaker, and what standard care would look like if exercise were genuinely part of it.

The discussion was designed to prioritise consumer voices and to keep the focus on lived experience. Researchers were present primarily to listen and capture insights, seeking clarification only where needed. Because of scheduling and the geographic spread of participants, some contributions were provided afterwards in writing.

Part 4. Photographs and discussion synthesis

The photographs selected by participants are presented in this report alongside the meanings and reflections shared during individual interviews and group discussion. The images were chosen not to illustrate predetermined findings, but to make visible what trying to exercise during cancer treatment actually felt like. By anchoring discussion in participant-generated photographs, patterns and contrasts across stories were able to emerge organically, forming the basis for the themes presented in this report.

All quotations in this report are the words of participants, taken from interview and group discussion recordings or from written captions participants supplied with their photographs. Participants are not identified by name, and personal names and place names have been removed or replaced in square brackets. Verbal fillers have been removed and ellipses mark where material has been omitted; no words have been added.

PARTICIPANT-SELECTED IMAGES AND THEIR MEANING

The dominant visual language of this group was light and darkness, blackness, torch beams, a lit page, moonlight on water, used to describe the absence of information as something physically experienced rather than simply missing. Alongside this ran images of pieces that do not fit.

1. In the dark: information as something you cannot see

Participants photographed darkness and light sources to describe not knowing that exercise mattered, or what was safe. Black frames, a torch beam on the ground and a page lit in an otherwise dark room conveyed an absence that was experienced as a condition rather than an oversight. These images were about the period when exercise was simply not present in the conversation at all.

2. One small voice in a cacophony: exercise drowned out

Images of overwhelming quantity — a page dense with the vocabulary of cancer, a daily plan of chemo and sleep, shelves of books — showed how exercise was pushed to the margins by the sheer volume of everything else. Participants described prioritising what was put in front of them, and exercise was never put in front of them. Where information did exist, there was too much of it and no way to judge what was credible.

3. Exercise as a missing piece

A jigsaw with the exercise piece outside the frame, a treatment-day plan without movement on it, and hazard tape across a doorway showed care that was thorough in its medical detail and complete in its own terms, yet organised in a way that left exercise out. Participants did not describe exercise as poorly delivered; they described it as absent by design.

3. Free fall: diagnosis with nothing to hold onto

Photographs of a skydive, a rusted figure in a salt lake and a person's own shadow described the speed, isolation and loss of self at diagnosis and immediately after treatment. Participants described falling through the experience without touch points, unable to see detail, and unsure whether anything would catch them.

5. Going in circles: climbing, sliding and starting again

A doll climbing and sliding back down a mound of earth, a seat that circles a tree, a rope web, an unused rowing machine and a single white line on an empty road described repeated effort that returned participants to where they began. These images carried real financial and emotional cost, and in one case, physical harm.

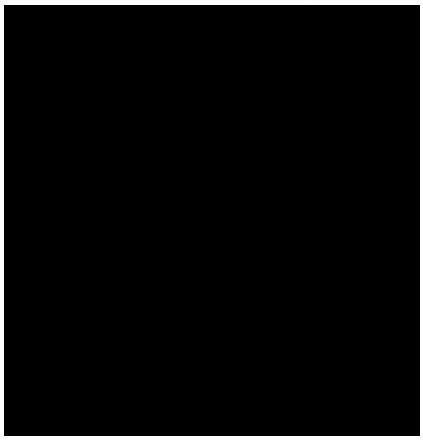
6. Light, movement and the way in

The same tree photographed across four seasons, a lighthouse seen from a distance and then gradually closer, and a tin man with an oil can showed what actually worked: small, local, incremental movement, undertaken on good days and bad, that opened the way to everything else.

1. IN THE DARK

Participants used darkness to describe the period in which exercise was simply not part of their care. This was not framed as a preference for more information, but as the experience of being unable to see what was there. One participant submitted a black frame as her first photograph. Her second was a torch beam thrown across the ground. Her third was light on water.

Another participant photographed a blank, lined page lit by a single torch in an otherwise dark room. The point of the image was that the light finds nothing. Participants described looking for information that was not there, rather than failing to look.

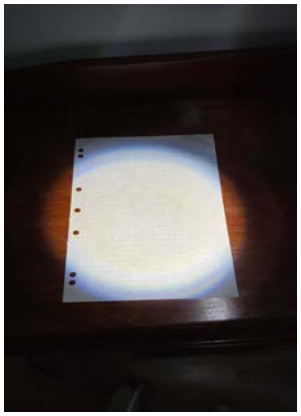


In the dark about exercise altogether

The light at the end of the tunnel

Still searching for answers

> *"I was pretty much just kept in the dark about what I should be doing to help myself in regards to exercise and movement."*
>
> *"The searchlight is pretty much me searching for answers in the dark, because, like I say, it wasn't part of my treatment plan, anything to do with exercise."*
>
> *"They don't have the motivation or they don't have the means to research as much as I have. Then they're in the dark and they stay in the dark, which is really sad."*



We are in the dark and we need to shine a light on what is needed, but the information is not there

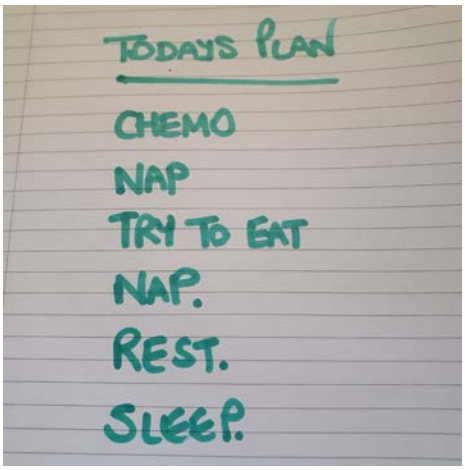
Back to YouTube...

> *"In that darkness, you might be looking for information, but there's nothing there. That's what that is."*
>
> *"There was no light on the real reason why you should push yourself to do this exercise."*
>
> *"I just thought, well, I'll just go on YouTube and do a search and see if I can find some information and programmes and just start doing it by myself."*
>
> *"I'm forever on Google trying to find answers. So yeah, YouTube, I went looking on YouTube because I couldn't find anyone to help me. And so I'm back to YouTube. Again today I'm back to YouTube."*

2. ONE SMALL VOICE IN A CACOPHONY

One participant wrote out the vocabulary of her cancer on a single page — surgery, biopsy, isotope, lymph nodes, ductal, DIEP flap, plastic surgery, reconstruction, bilateral mastectomy, hormone therapy, lymphoedema garments, health insurance, out of pocket, money, work, family, grief, sadness — and wrote the word "exercise" in small red pen among them. When she showed the photograph, the person viewing it could not find the word. That was the point of the image.

It is one small voice, in a cacophony of sound



Today's plan: chemo, nap, try to eat, nap, rest, sleep

> *"When you're going through it, there's lots and lots of things you're dealing with. There's terms you've never heard before, there's people treating you different... And you may have been told about exercise, but it's that tiny little one down there. But it just doesn't get through half the time, or more than half the time."*
>
> *"I prioritise what I'm dealing with, and that wasn't given as a priority, so it just sort of fell into the background, which is what that's done."*
>
> *"That's why I put it in red, to be honest, because you'll never find it otherwise."*
>
> *"No, no, no exercise."*

A second participant photographed the plan she wrote for herself on a treatment day: chemo, nap, try to eat, nap, rest, sleep. Movement is not on the list. She described the year in which she was treated as one of survival rather than choice, and said that a plan would have changed what she did.

> *"Just basically survival, because I honestly thought I was going to die."*
>
> *"I think if there had been a plan in place for exercise, I would have been able to manage it because I would have known it was important in my recovery. So I would have done it."*

A third participant photographed two sets of books: a shelf of beautifully produced volumes, and her own pile of old, shabby ones. She used the contrast to describe a different kind of noise — not too little information, but far too much of it, arriving at a moment of maximum vulnerability, with no way of telling what was credible.

The glossy and the well presented

The shabby ones, where the real gems are

> *"What I found was actually there was so much information out there, but it was all hidden amongst all various different booklets and information that we're given."*
>
> *"It's very easy to end up getting our exercise information from influencers or things that have gone viral or things that, you know, the glossy leaflet rather than the really credible one."*
>
> *"We're overloaded with information, but we want information, but we've got to be careful that we don't go to the shiniest, most well presented as opposed to the best."*
>
> *"We're very vulnerable at that time. So we will just, you know, we all got, I mean, I took all of those council leaflets that you could get."*
>
> *"It needs to be simplified and accessible and easy, so that people can stick it on the fridge."*

3. FREE FALL

A participant who had competed in triathlon before her diagnosis submitted a photograph of herself skydiving, taken decades earlier. She used it to describe the period after diagnosis: speed, isolation, detail rushing past too quickly to grasp, and no way of knowing when or whether anything would open to support.

Life after cancer treatment felt like a leap into the unknown... Exercise eventually became the parachute I didn't know I needed. Support was possibly available but awareness wasn't.

> *"I look so little in that photo and it's just the whole wide world's, I'm falling into it. And it is a free fall. It's like, you don't know when the shoot's going to open. You don't know when you're going to get saved."*
>
> *"You don't know when you're going to see something like exercise and go, oh, that will actually help me. You're just sort of going through it, not aware... You're not seeing all the little parts that could benefit you, that could help heal."*
>
> *"You don't know if you'll survive that jump and you also don't know if you'll survive the cancer. So they sort of, and they both happen fast."*

Another photograph showed a rusted metal figure in a dry salt lake, one of the most isolated places she could find. She named the image "inner child" and described looking around for help that was not there. Another participant photographed her own shadow on the road and used almost identical language.

A shadow of myself... There was no pathway to follow, no direction from professional health workers.

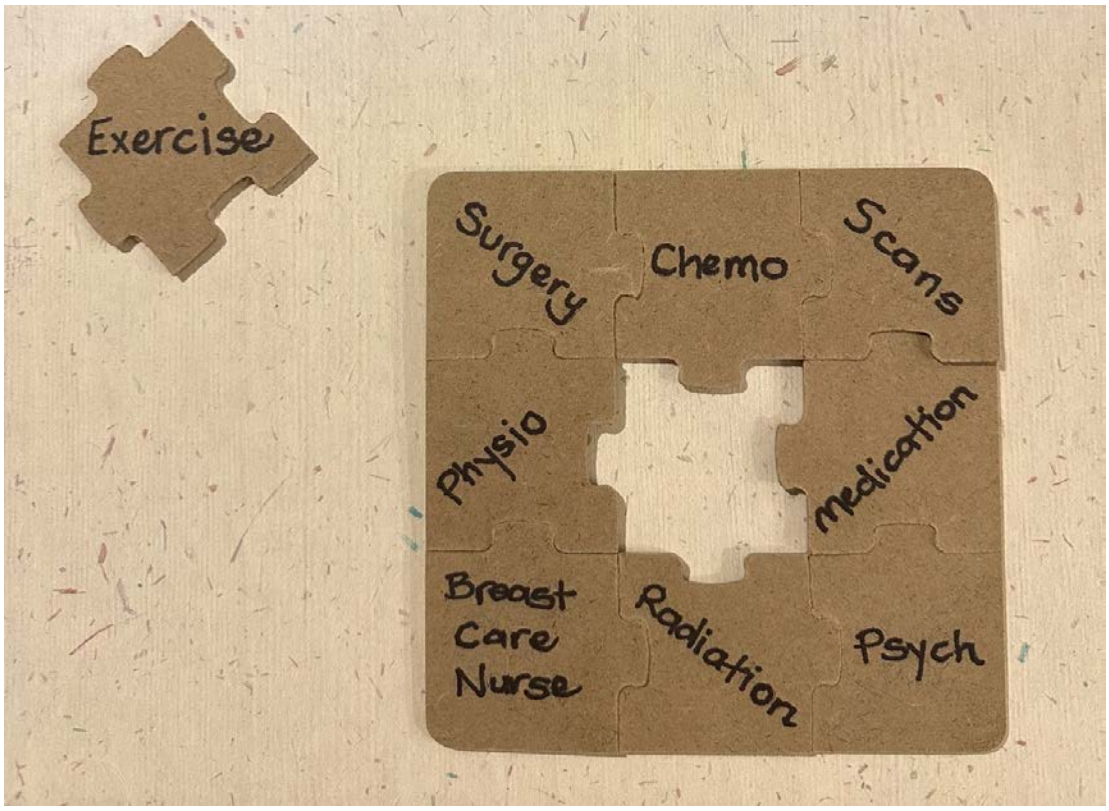
My shadow — well, where now? What should I be doing?

> *"After cancer treatment, I stood in unfamiliar territory. A shadow of myself. I had stopped exercising as I wasn't sure what I was capable of. There was no pathway to follow, no direction from professional health workers. Exercise is the most important tool for recovery... yet there was no obvious opportunities to access."*
>
> *"I'm in a desert there... I'm in one of the most isolated places, and there's, if you look around, there's no help available, there's nobody there to guide you."*
>
> *"The inner child was active, and the inner child, you know, but in that photo, the inner child's rusted."*
>
> *"There's not that added caretaker, the one that sort of goes, oh, your nutrition and your exercise together, they will heal you."*

4. THE MISSING PIECE

One participant made a jigsaw. Surgery, chemo, scans, medication, physio, radiation, the breast care nurse and psychology all interlock. The exercise piece sits outside the puzzle, waiting to slot into place. She described exercise as the piece that would have connected everything else, and the only one she was never given.

Another participant photographed hazard tape crossing a floor, with a single footprint between the strips. She described coming out of surgery unable to straighten her body, with several clinicians each telling her what not to do and none telling her what to do.



Exercise is the missing piece, which connects all of those things

> *"You've got all your different stages in your treatment journey. Exercise is the missing piece, which connects all of those things."*
>
> *"Exercise after surgery is so important, but you don't get told that. During chemo, it's so important because exercise just helps your body move and it helps the chemo go through your body."*
>
> *"It's such an important piece and it's missing."*
>
> *"It's not something that you're told, which is really bizarre to me."*

Sometimes it just feels a step too far

> *"You come out of surgery, you're going into other stuff and exercise because, you know, you're in bits and pieces, you're a bit like a patchwork quilt and you've got bits cut out of you that you can't move like you used to... So, exercise just seems a step too far."*
>
> *"You've got people saying, no, you can't move that arm... you can't even straighten your body because you've had a DIEP flap done. So how the hell are you going to navigate exercise?"*
>
> *"There's more not what not to do than what to do."*
>
> *"Other people who love you want to wrap you in cotton wool because you are pretty sick. And so to go and do something strenuous is a step too far for yourself because you don't want to fall in a heap."*

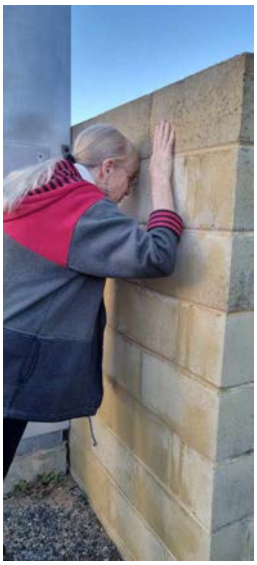
5. GOING AROUND IN CIRCLES

One participant had placed a doll on a mound of earth in a local park to represent climbing up a huge hill before being forced back down. Similarly, photographs of a circular bench around a tree as a merry-go-round she could not get off, a rope web she was caught in, a wall she was hitting her head against, and finally herself, crying.

Climbing up the mountain, and sliding back down to the bottom again

On the merry-go-round, with no way of getting off

Stuck in the web of a lack of holistic care



Smashing my head against a brick wall

“I'm climbing up a mountain and I'm almost at the top, and then I keep sliding back down.”

“I can't get off the merry-go-round because, yeah, there is no solution here... I'm on the merry-go-round and there's just no getting off. It's just going to keep going round and round in circles. And yeah, here I am back at the beginning again.”

“If you get stuck in a web, you're going to get eaten by the spider in the end. And I guess the spider is the cancer, which is eating my spine.”

“Still feel like I'm smashing my head against a brick wall. And it's scary. It's painful, because am I causing myself more pain?”

“There isn't holistic care — that doesn't exist in the medical model at all.”

She asked that the final image be included. It is a photograph of herself, taken at home, in the middle of writing up what her other photographs meant. She described two distinct kinds of grief: the grief of the cancer itself, and the grief of not being able to get help.

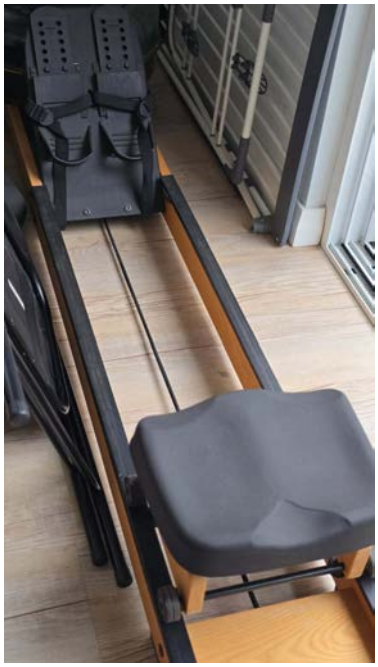
There's the grief of cancer and what you lose, but then there's the grief of I can't get the help

“There's the grief of cancer and, you know, and what you lose, but then there's the grief of I can't get the help. And so I've got all this extra grief due to the inadequacy of the medical model to care for me, to keep me going in wellness direction.”

“That's actually a real, real crying, because that's what I just suddenly thought, I should take a picture of this because this is real.”

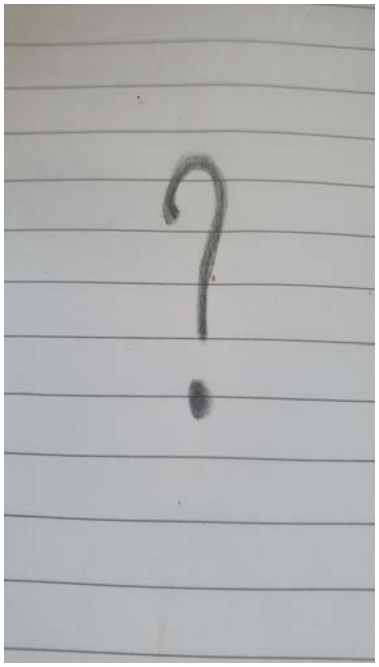
“I'm very passionate about this because it's atrocious what's happening to me, absolutely atrocious. And if I can make some change to others, well, wonderful, but it could even benefit me if I'm still alive.”

Two further images in this theme came from other participants. One photographed a rowing machine that had been given to her and never used; the other, a single white line on an empty road, which she described as keeping on keeping on with nowhere else to turn off to.



Great intentions

Keep on keeping on — no pathways anywhere else



Where do I go from here?

> *"We all have great intentions, but you just, life gets in the way and you don't do it. You get sidetracked. So we've all had that piece of machinery that you bought with great intentions and then it sat in the corner of the room."*
>
> *"It's just a dust gatherer at the moment."*
>
> *"My question mark was, where do I go from here, basically? I felt a bit abandoned, I think, because [the oncologist] signed me off straight away. So it was like, what now?"*
>
> *"You're on your own. Just feel very lonely, I think, because you're on the journey on your own."*
>
> *"No pathways anywhere else. Just keep on keeping on."*

6. LIGHT, MOVEMENT AND THE WAY IN

One participant, living in a small town some distance from any gym or exercise service, walked the same arboretum every day through her treatment year. She photographed the same tree across the seasons. The images track her fitness and her mood together: dry and red in autumn, bare in winter, in full leaf by summer. She also photographed the tree's exposed roots, dry for most of the year and submerged in spring, to make the point that movement alone is not enough without nourishment and support.

The same tree, photographed across a year of treatment. It's no good doing the exercise and the fitness on your own — you need that kind of nourishment.

"When you're having treatment, you go through various ups and downs and different kind of seasons of not only physically, but mentally what you're actually thinking."

"Walking around the tree park every day was physically the exercise that I needed, but also mentally the exercise that I needed."

"It was my gateway drug to exercise."

"The treatment wasn't being done to me, I was choosing to do something. I was being proactive about my treatment."

"Some days I couldn't do a lot of exercise, but the idea was a little is enough."

"You don't need to do a massive long walk or you don't need to do a lot of exercise. You just need to kind of start and get going and be aware that there will be different seasons of your exercise routine."

The same participant photographed the lighthouse near her home three times: distant across scrub and surf, close but shrouded in mist, and finally with a clear path leading to its door. She used the sequence to describe exercise as a goal that stays permanently on the horizon — something to do "when I feel better" — and the work required to bring it into focus.

Exercise as something in the distance, for when you feel better

Even when you get there, you still have to climb it

A clear path to exercise

> *"I knew that exercise was something that I needed to do, but you'll see it's kind of on the left, it's a long way away. It was this kind of thing on the horizon that I thought, yeah, I've got to get to that."*
>
> *"Even when you know that that's what you've got to do, there's still the steps to climb and there's still the last bit of navigation to actually find an exercise physio or someone that understands our specific needs."*
>
> *"Rather than having the lighthouse of exercise somewhere in the distance, we put it a little bit more into focus. We try and help people navigate the barriers so that then they can actually feel that they can achieve something."*
>
> *"You need someone to help you navigate through that, and you need someone that helps you on those steps, and you need not just the encouragement, but the practical aids."*

The remaining images in this theme describe what movement does once it is happening. One participant printed a tin man, cut it out, mounted it on a skewer and stood it in her garden with an oil can. Another described discovering swimming only because a physiotherapist she trusted told her to do it — an activity she had never chosen for herself and now does regularly. Both images make the same point: the benefit was real, and neither of them found it through their cancer care.

When I exercise, it's like oil for my joints

Where do I start? How much? What is safe?

> *"When you're going through all the treatment, particularly like now with the medication, it makes you really stiff and sore. And I know that when I exercise, it's like oil for my joints."*
>
> *"Although it's hard to get motivated because you're tired and you're sore, when I get out there, even if it's just a walk, it just feels like an oil to my joints and I feel so much better after."*
>
> *"I wasn't sure what exercise I could do, how much I should do, which way to go, what was too much, what was too little, what was going to be beneficial, what wasn't. So it was just a lot of question marks around what exercise that I should be doing."*
>
> *"I got it from a physio that was recommended by my surgeon... And I'm not a swimmer, so it's not something I would have naturally done. But as it turns out, I did it because I wanted to get better, and I got it from a credible person... And so I've just kept it up. So it's something I wouldn't have done."*
>
> *"It's opened up something that I wouldn't have done. So there are possibilities there that you don't know."*

THE CONSUMER CONVERSATION

The following findings are drawn from the six individual interviews and the group Micro Community Conversation. They are presented in the order participants themselves tended to move through them: first what is missing, then what would fix it, then what stands in the way.

1. EXERCISE SITS OUTSIDE THE TREATMENT PROTOCOL

Every participant reported the same finding from a different starting point: exercise was mentioned once, vaguely, by one practitioner, or not at all. One participant had a diagnosis in 2016 and a second in 2025 and could compare the two directly; she reported that almost nothing had changed. Another raised the issue with her oncologist during the project itself and was told plainly that exercise sat outside the protocol he was required to follow. Participants understood this as a system constraint rather than individual indifference, which made it more troubling rather than less.

> *"He repeated himself a few times saying, it's not part of our treatment protocol or plan and not part of what they offer. He has to follow a protocol, and exercise isn't part of that protocol."*
>
> *"No wonder we are having to try to access exercise. It's not going to happen through the cancer care system, which is oncologist, that's the person you're seeing all the time."*
>
> *"One more thing that was said to me by the oncologist is most people don't want to know about doing exercise... He never offered me that, did he?"*
>
> *"Dr [name] did mention, you know, it's good to exercise while you're having chemo. That's the last time I heard exercise mentioned."*
>
> *"It was never routinely brought up that you need to exercise, or it wasn't part of a treatment plan like other things that were offered."*
>
> *"Nobody expected me to exercise during treatment the first time at all, I don't think. Not when I was having chemo... The second time, it was mentioned, but it was more like, you know, try and walk, try and go for walks."*
>
> *"That seems to be a systematic thing."*
>
> *"It's absolutely appalling because doctors do know about exercise. If you go and speak to a heart specialist, that would be part of the treatment plan. But here we are with serious cancer and it's not part of the treatment plan."*
>
> *"Like people that have heart surgery, the cardio teams are really good at that... exercise is given to you on the sheet of this is what you've got to do."*
>
> *"I've not seen anything. No, not in my time anyway."*

2. "IF IT WAS GIVEN TO US, WE WOULD DO IT"

The group discussion opened its first question with this sentence, and the rest of the conversation returned to it repeatedly. Participants were emphatic that the barrier was not willingness. What they described needing was a plan with the same status as the rest of their treatment: introduced at diagnosis, reinforced by every practitioner they saw, tailored to their surgery and their side effects, and followed up. Several also asked for the evidence itself, the figures, not reassurance, as the thing that would motivate them.

> *"If it was given to us, we would do it. But it needs to be in a safe path."*
>
> *"It needs to be part of that treatment plan, because you can't just have a one-size-fits-all... So that system needs to change."*
>
> *"Every professional you see should be telling you about exercise, but also I think there should be a programme as part of our holistic care and our care plan where they can refer us to."*
>
> *"This is the benefit of the exercise. Like they're telling you the benefit of chemo and radiation and surgery. This is the benefit of exercise. This is how it's going to help you... I would get on and do it. I'd be like, yes, this is part of my treatment plan."*
>
> *"I think if there had been a plan in place for exercise, I would have been able to manage it because I would have known it was important in my recovery. So I would have done it."*
>
> *"You're having chemo and you have to have radiotherapy and you have to exercise. Be nice to have all three grouped together."*
>
> *"I think the conversation should also be brought up by the specialist in the very start... It can be followed through by all the practitioners that you see."*
>
> *"If I'm told to do something, I do it."*
>
> *"I'm a people pleaser sort of follow the rules person. So if a doctor or somebody... says to me, right, this is week three after your mastectomy, what you need to do is, I'll follow the plan, I'll follow it to a tee."*
>
> *"If I'm given a set plan, I'll do it... and honestly, some sort of check-in, like accountability."*
>
> *"It was the data, it was seeing the stats and the percentages and the figures. And then it was like, well, how can I not do it then?"*
>
> *"I just wanted to be told what to do, because you're not psychologically going to come up with your own programme... you're very vulnerable at that time."*
>
> *"If I had a cheat sheet of it, I would do it."*
>
> *"If I'd known exercise was so important with chemo, I definitely would have done it, that's for sure."*

3. MIXED MESSAGES AND THE CULTURE OF REST

Participants described a system that, when it spoke about movement at all, spoke about it inconsistently. The most striking example came from a participant who walked for half an hour after each chemotherapy cycle, having worked out for herself that it helped. When she told the treating nurse, she was corrected. The same pattern appeared across surgical teams, in the messaging participants received from family, and in the wider cultural picture of what a person with cancer is supposed to look like.

> *"The nurse said, what are you doing now? And I said, oh, we normally go for a walk... And she was shocked. She's like, what, you're going for a walk? You have to go home and rest... She said, oh, I think you should probably only do 10 minutes max. So even from the nurse, that was the message that I got."*
>
> *"They think anyone that's having chemo should take care of themselves by resting and perhaps eating well but taking it easy."*
>
> *"In the treatment phase, they're going, what the hell are you doing? You should be just resting. That's the attitude."*
>
> *"I don't think, when people hear you've got cancer, the last thing they think you're going to do is go for a run. After chemo, after you've just had all this poison put in your body, that's the last thing people think you're going to do. They would be going, oh my God, are you nuts?"*
>
> *"One thing I did think, and that's probably weird, but I thought if I exercise, it's going to move the cancer around."*
>
> *"It's more cloudy in the treatment sector because you've got, what, three different people with a say in your activity. You've got your surgeon, you've got your oncologist, and you've probably got a plastic surgeon as well."*
>
> *"They should probably discuss what level of exercise they're going to recommend as a team, because one will say one thing and one will say another and you don't... I've got no idea."*
>
> *"In the movies, if someone's going through chemo, they're spewing in the toilet and they're lying on the couch and they're so sick as a dog. They're not doing anything."*
>
> *"The image of cancer is that doom and gloom and you're frail, you need looking after."*
>
> *"My oncologist's... whole advice was, oh, it's okay to have a bit of a cake now and again, and maybe a drink now and again. And I thought, well, that was a weird thing to say, to be honest."*

4. THE BURDEN AND COST OF SELF-NAVIGATION, AND WHO CAN AFFORD IT

Self-navigation was described not as autonomy but as unpaid, exhausting and expensive work, undertaken while unwell. Participants who succeeded attributed their success to research skills, insurance, income or sheer stubbornness, and were explicit that these are not qualities a care system should require. The group returned repeatedly to the people who would not have those advantages.

> *"This system has failed me."*
>
> *"There's also no income, so I can't join a gym. Joining a gym's out of my reach... It's restrictive in as much as I don't have access to anything."*
>
> *"All this has cost me a lot of money too. And it's not just physios I've been to."*
>
> *"I'm in private rental and I'm on a pension... it takes over 60% of my pension, which isn't a lot of money."*
>
> *"I was seeing a community health physio, because we couldn't afford to keep having physio through the private sector."*
>
> *"Very unfair, yeah, unfair system."*
>
> *"I'm blessed enough to be able to have private health insurance to be able to go and see a private physio, a lymphoedema physio, and a lot of people don't have that."*
>
> *"I think everyone has the right to have the same treatment, no matter what stage they're at or what they have at their fingertips."*
>
> *"I thought I'd won the lottery and got this exercise physiologist who was therapist number 11 in the last just over 12 months."*
>
> *"I'm younger, so I've got more knowledge of the internet and that sort of thing, and I can research. Whereas someone who's older than me... wouldn't have a clue how to even use an email."*
>
> *"It costs me more to have my breast cancer sorted than anybody I know. And we've got full private health care."*
>
> *"I'm a very resourceful person. I've worked in human services all my life, so I'm just on a mission now, like I used to do for my clients."*
>
> *"It was literally my own determination."*
>
> *"I'm doing well, but only because I'm highly motivated; otherwise, I think some people would have really given up."*

5. WHEN SUPPORT IS UNGUIDED, IT CAN CAUSE HARM

For participants who did reach an exercise provider, care was not always safe. One participant with extensive spinal metastases found an exercise physiologist through an oncology directory, was given a program that included spinal rotation, and was in severe pain within a day. She identified the problem herself, after her sister queried the movements and she cross-checked them online. Another declined the strength program written for her at a local gym because it included exercises, she judged unsafe after reconstruction. Participants consistently attributed this to a training gap rather than to individual practitioners, and asked for accredited, cancer-specific expertise that works alongside the treating team.

> *"She gave me these exercises and then I was in a lot of pain — I could hardly get out of bed the first morning after doing these exercises. And then talking to my sister, who's lived with a spinal fracture for many years, she said, you can't do those movements with a spinal fracture."*
>
> *"I get scared thinking... have I now got some further damage, because my spine feels weird?"*
>
> *"There should need to be exercise physiologists that are specifically trained in what I've got, which is metastatic spinal injury. There isn't one that I can find."*
>
> *"There's a big gap, obviously... there's a gap somewhere where we're not training them here."*
>
> *"They're just not able to understand how to help me because they don't have the training, so it's not her fault."*
>
> *"I've come to the realisation that what I'm looking for actually doesn't exist here. It doesn't exist."*
>
> *"I'm grateful for YouTube... It can also be dangerous, giving the exercises that probably aren't appropriate for me."*
>
> *"Initially he's giving me loads of like push-ups and things. And I'm thinking, well, I'm not doing that because I'm worried that my reconstruction is just going to burst open."*
>
> *"Some of the exercises even that my physio gave to me were a bit too much, and I found that when I did them, it actually aggravated my arm."*
>
> *"What I'm wanting from an exercise physiologist is a programme to strengthen the muscles that support my spine to make it possible for me to be as independent as possible for as long as possible."*
>
> *"The exercise physiologist or physiotherapist would be working in close connection with your oncologist... they should all be meeting so that I'm getting a proper, good rounded care."*

6. DISTANCE, AVAILABILITY AND IMMUNITY

For this group, access was shaped less by willingness than by what physically existed within reach, and by whether being in that place was safe. Participants living in small towns had no local gym, exercise physiologist or class. Programs that did exist ran infrequently, could not always be repeated, and were often held elsewhere. Layered over this was immune status: several participants avoided public gyms entirely, and one had been hospitalised with influenza during chemotherapy. What participants asked for was small, cancer-specific groups located where they already had to be.

"The barrier becomes because I'm living in [a small town] in the middle of nowhere... We don't have a gym and exercise physiologists and classes, and I was a couple of hours away from anything like that."

"For rural and regional people, there's that extra layer of, well, how do you do exercise when there aren't people around?"

"I do the three hour round trip for an 8 minute appointment... If they'd have said, well, drive in and do a one hour guided exercise session, I would have done it, because I was driving for the 8 minute appointment."

"I signed up for that, but that only runs one or two times a year down here... And even that one, they don't always run it down here."

"If we had something like that ongoing, it would be great."

"It opens it up to the whole of Australia, really — people in remote areas."

"There was nowhere I could go. I couldn't go to a breast cancer gym. There wasn't a free gym around."

"Going to the gym and having everyone sweating over everything and then sitting on the equipment after them, it just grosses me out and I worry about picking up something."

"I ended up getting influenza A and ending up in the hospital for like 4 days. I was so sick. That was really scary."

"If you're just going to your local gym, every man and his dog's there, and they don't know you're immunocompromised."

"About two weeks later, I was bald and I still had drains hanging off me. And it was then I thought, a little bit self-conscious, don't want to go out in public."

"If it was in the same area as you have chemo, with radiotherapy, that'd be perfect... because you don't feel like going anywhere else. And if it was next door, it would be really, really helpful."

"If there was something like... a small gym and there was a small amount of people, for sure I would have done that."

7. THE WHOLE PERSON, BELONGING, AND THE CASE FOR CHANGE

Participants made two arguments in parallel. The first was ethical: that treating the disease without treating the person is incomplete care, and that movement is the part of a human being that the system has left out. The second was economic, and participants made it deliberately, noting that this was the language decision-makers would respond to. Alongside both ran a quieter theme about belonging - accountability, buddies, small groups, and being among people who understand - which participants identified as part of what makes exercise actually happen.

> *"You're treating other things with chemicals and ways to kill the cancer, but you're not treating the whole person."*
>
> *"Where's the wellness treatment? There isn't any that exists. We're not even talking to people about nutrition, let alone the exercise."*
>
> *"Exercise is the most important thing for me to have a future where I can self-care and be independent as possible, and less reliant on a lot of health care services."*
>
> *"We don't want disabled people because the system has let them down in one aspect of our human being, which is the movement aspect."*
>
> *"You're going through something that's costing thousands upon thousands. Why wouldn't you make the most of anything that's going to increase your likelihood of a good outcome?"*
>
> *"A lot of things come down to the bottom line, and you have to talk their talk."*
>
> *"They're spending more money in the long run."*
>
> *"If I was accountable and I had that available, I would go to it... because I know if in the past I've had a walking buddy or had someone to go to the gym with, I'm accountable to them to go."*
>
> *"Having like-minded people who understand your journey would be amazing."*
>
> *"It just needs to be one, a buddy, someone that you can meet with every so often and grab a coffee and go for a walk."*
>
> *"If you belong, if you feel that you fit in, you're going to respond better than if you feel like you're a reject."*
>
> *"We need to kind of almost rebrand what exercise can be, so that people do get introduced to it in a very positive way."*
>
> *"I don't want to be defined by cancer."*
>
> *"Making the most of our lives now, because we know life can be short."*

USE OF PHOTOVOICE FOR DEEPER UNDERSTANDING

Photovoice was well suited to this topic because the barriers participants faced were not discrete events that could be listed. They were conditions — not knowing, not being told, not being able to see a way through — that are difficult to surface through service-focused questioning but were immediately legible as images.

The visual language this group reached for is itself a finding. Six people, working independently across four weeks and several hundred kilometres, produced photographs of darkness, torchlight, free fall, shadows, missing pieces and circular paths. None of them had seen the others' work. The convergence gave participants confidence that what they had experienced was structural rather than personal, and it gave the research team a shared vocabulary that no interview schedule had supplied.

Photographs also carried things participants found difficult to say directly. One participant used a doll to represent her own body on a hillside and show herself sliding back down it. Another used a jigsaw to show that the omission of exercise was not a gap in her care but a shape her care had been built around. A third used a page of her own handwriting to demonstrate, rather than assert, that exercise had been unfindable among everything else.

The process had a further effect that participants named themselves. Several described the interviews and the group conversation as the first time anyone had asked what this part of their experience had been like, and the first time they had heard it echoed back. One participant, who had spent more than a year seeking appropriate support without success, described the process as healing and said she had found her voice through it. Another said that reflecting on her images had made her realise for the first time that exercise had never been part of her treatment plan at all.

> *“I wrote, I found my voice at last. Like being here with you and being part of this, I have found my voice.”*
>
> *“Doing this project has made me really reflect on the journey when it comes to exercise... reflecting on it now, I realise that it wasn't part of my treatment plan and it wasn't mentioned by any of the professionals that I saw.”*
>
> *“It's not wasted. So what I've gone through, I hope won't be wasted.”*

MICRO COMMUNITY CONVERSATION: QUESTIONS AND RESPONSES

After viewing the full collection of photographs, participants were asked three structured questions. Responses to the first two were given in the group discussion and are summarised below. The third was taken away for written response, and the material presented here is drawn from what participants described in their individual interviews when asked to imagine a different system.

Question 1

Looking across all the photos and stories: what themes keep coming up, and what do they tell us collectively about what it is like to try to access exercise during cancer care in Australia?

Participants converged quickly on a single answer: people want to exercise, and the system does not offer it. The group described a pattern in which the desire and the willingness were present throughout, but nothing in the care pathway met them. Exercise was characterised as a minefield to be crossed alone, at a time of minimum capacity, with no map and no confirmation that any particular step was safe. Participants emphasised that this was not a matter of individual clinicians failing, but of a protocol that does not contain exercise and a workforce that has not been trained for cancer-specific needs.

The group also identified the consequence: because access depends on what an individual can find out and pay for, outcomes diverge sharply between people with the same disease. Participants who had done well named research ability, insurance, income and stubbornness as the reasons, and were uneasy about it.

> *"If it was given to us, we would do it. But it needs to be in a safe path."*
>
> *"Everyone's in the dark and struggling and don't know where they're going or what they're doing. And it was just like a minefield. That was the things that I saw coming up."*
>
> *"It needs to be part of that treatment plan, because you can't just have a one-size-fits-all, because we've all had different barriers from our treatment put in place."*
>
> *"A lot of us have the motivation to do it on our own and find it for ourselves. But some people don't... and they just aren't aware and they're not told so they don't find out. And then that can impact them for the rest of their life after their cancer diagnosis in a negative way."*

Question 2

If a funder or policymaker was sitting in this room right now and had just seen everything you have shared: what would you most want them to understand, and what would you ask them to do?

Participants made three arguments. The first was clinical: an appropriately trained and accredited exercise practitioner should sit inside the multidisciplinary team from the point of diagnosis, in the same way that a breast care nurse, surgeon, oncologist and plastic surgeon already do — so that the patient is on their books automatically and does not have to seek them out or repeatedly explain their own limitations. The second was that this practitioner must be involved early, so that a plan can be tailored to the whole person, including other chronic conditions, and adjusted over years rather than weeks.

The third argument was economic, and participants made it deliberately. They pointed out that the system already spends very large sums on surgery, chemotherapy and radiotherapy, and then declines to protect that investment; and that the downstream costs of deconditioning, disability, aged care and lost independence are borne by the same public purse.

> *"You know how you go and see your oncologist and they have a team, they talk about you in a team situation. It might be a breast nurse, your oncologist, your surgeon, your plastic surgeon. Why isn't there a...?"*
>
> *"You're on their books automatically. You're not having to seek them out. And they know everything already... that's part of the hamster wheel."*
>
> *"From the very beginning, so that they can tailor your exercise plan to your journey, and to factor in all the other aspects in your life — if you've got other chronic illness, if you've got other conditions, limitations... They can tailor your plan for your journey onwards for the years to follow. And they can monitor you."*
>
> *"You're going through something that's costing thousands upon thousands. Why wouldn't you make the most of anything that's going to increase your likelihood of a good outcome?"*
>
> *"We spend all this money on radiation... and chemotherapy. And it does create issues further down... If it was holistic, the likelihood of that cost being reduced is good."*
>
> *"What I would most want them to understand is that exercise is the most important thing for me to have a future where I can self-care and be independent as possible."*
>
> *"I would ask them to... start valuing that we're holistic beings. We're not just people that are sick."*
>
> *"It opens it up to the whole of Australia, really — people in remote areas."*

Question 3

If exercise was genuinely part of standard cancer care — offered to everyone, wherever they live, whoever their doctor is — what would it look like, what would it change, and what would be the impact?

Participants described a system in which exercise is introduced at diagnosis by the specialist, repeated by every practitioner the person sees, and delivered as a named appointment rather than an encouragement. Several proposed that the session be co-located with treatment — in the same building as chemotherapy or radiotherapy, immediately before or after — on the grounds that people will not make a second trip but will readily walk down a corridor. Participants asked for the program to be small, cancer-specific and infection-conscious, and for it to continue for six months to a year after treatment rather than ending with it.

They also asked for something simpler than what currently exists: a single, short, credible sheet of instructions that can go on the fridge, in place of dense booklets; realistic, individual goals set with someone who understands what their surgery has changed; and the actual evidence, including the effect on recurrence, stated plainly.

> *"If it was in the same area as you have chemo, with radiotherapy, that'd be perfect... because you don't feel like going anywhere else."*
>
> *"I really wish that I had a programme to go to every single week, a few days a week, that was specifically tailored to cancer patients and the issues that they face through treatment and at different stages... Small group, get to know people, be accountable."*
>
> *"Definitely six months to a year, I think, afterwards."*
>
> *"I think there should be a separate appointment that you have really early on... so it's in the language, it's in the narrative right from the beginning."*
>
> *"We need facts, very factual, even if it's scary — the facts and figures about what happens if you don't do exercise and what happens if you do."*
>
> *"A programme that is simple, straightforward, that gets people started. Because I think once they start, and they start to feel the benefits, then they will seek out more and do more."*
>
> *"We don't need 80 pages in a booklet."*
>
> *"Realistic, achievable goals, and paced at something that's not going to injure you, because I think people feel very vulnerable afterwards."*
>
> *"It should be the responsibility of the government to incorporate this into cancer treatment... it should be part of the holistic care, because it is so important."*

WHAT PARTICIPANTS SAID MATTERED MOST

Theme	What participants said
Exercise must be prescribed, not suggested	– Participants said, without exception, that they would have followed an exercise plan given with the same authority as chemotherapy or radiotherapy – A single passing mention by one practitioner was not experienced as advice – What was asked for was a plan, a reason, a named person and a check-in
The problem is not motivation	– Every participant sought out exercise information themselves, while unwell – Several exercised throughout treatment on their own initiative and could describe the benefit precisely – What stopped people was not knowing what was safe, not who was willing
Exercise has to be in the protocol	– Participants were told directly that exercise sits outside the treatment protocol – Comparisons with cardiac rehabilitation were made repeatedly and pointedly – A ten-year gap between two diagnoses showed participants that little had changed
Unqualified support can do harm	– Two participants were given exercises that caused pain or that they judged unsafe – Participants attributed this to a training gap, not to individual clinicians – Accredited, cancer-specific practitioners working alongside the treating team were the request
Bring it to where people already are	– Co-locating exercise with chemotherapy or radiotherapy appointments was strongly favoured – People will not make a second trip, particularly from a regional area, but will walk down a corridor – One participant drove three hours for an eight-minute appointment and would gladly have exercised there
Small, cancer-specific and infection-conscious	– Several participants avoided public gyms entirely because of immune status – Self-consciousness during treatment was a real barrier to mainstream settings – Small groups of people with shared experience were valued for safety and for belonging
Short programs are not enough	– Time-limited programs were described as helpful but insufficient – Support was needed for six months to a year beyond treatment, and longer on hormone therapy – Local programs ran once or twice a year and could not be relied on
Simple, credible, actionable information	– Dense booklets went unread; participants asked for a short sheet they could put on the fridge – Credibility mattered more than presentation, and participants worried about glossy but unreliable sources

Theme	What participants said
	– The evidence itself, stated plainly, was the strongest motivator participants named
Access is currently a matter of luck	– Outcomes depended on insurance, income, research ability, confidence and postcode – Participants who had done well named those advantages and were uneasy about it – Participants described the current arrangement as unfair rather than merely imperfect
Treat the whole person	– Participants described care that addressed the disease and ignored the body living with it – Nutrition, function, independence and mental health were raised alongside exercise – The economic case was made explicitly: protect the investment already made in treatment

WHAT LIVED EXPERIENCE REVEALS ABOUT EXERCISE ACCESS

This Micro Community Conversation brought together photographs, individual interviews and group discussion from six women treated for cancer, most of them living outside the Perth metropolitan area, with diagnoses spanning a decade. Across very different circumstances — early-stage disease and metastatic disease, private and public care, city hospitals and small towns — participants described the same thing.

Exercise was not part of their care. It was mentioned once, or vaguely, or not at all, and it was never followed up. Participants did not experience this as a service being under-resourced; they experienced it as a system built without exercise in it. One participant was told this explicitly by her oncologist, who said the protocol he worked to did not contain it.

What participants did about it was to go looking. They searched online, followed YouTube channels, read Cancer Council booklets, paid for private physiotherapy, questioned nurses, and pieced together programs from whatever they could find. This work was done while fatigued, in pain, immunocompromised and frightened, and it was expensive. Success depended on private health insurance, disposable income, research literacy, confidence and time, which is to say that it depended on advantages unrelated to clinical need. Participants named this as unfair and were troubled knowing many people would not be able to do this themselves.

Two findings from this conversation extend what a previous group (separate report) described. The first is that unguided access is not neutral: reaching a practitioner without cancer-specific training resulted, in at least one case, in a program that caused significant pain and possible physical harm, and in another in a program that was declined as unsafe. The absence of a trained workforce is therefore not only a gap in provision but a risk. The second is that geography and immune status jointly determine what is practically possible. Participants living regionally had no local service, and programs that did exist ran once or twice a year. Participants who were immunocompromised would not enter a public gym at all. Both point to the same solution: small, cancer-specific sessions delivered where people already have to attend.

Participants were equally clear about what works, and the evidence for it sits in their own photographs. Walking, undertaken locally and incrementally, was the entry point that made everything else possible. Instructions from someone credible were followed to the letter, including by people who had never done the activity before and did not expect to enjoy it. Accountability — a buddy, a group, a scheduled session, a daughter who rings up — was described as the difference between intending and doing. And the benefits participants reported were not abstract: range of movement sufficient to lie in the radiotherapy position, joints that moved in the morning, fatigue that lifted, mood restored, and independence retained.

The conclusion participants reached collectively was that responsibility is currently in the wrong place. Access to evidence-based exercise support is being treated as something patients must discover, justify and fund at the point of least capacity in their lives. Participants asked instead for exercise to be embedded by design: introduced at diagnosis, delivered by an accredited practitioner inside the treating team, tailored to the person's surgery, side-effects and other conditions, available locally and safely, and continued well beyond the end of active treatment.

“If it was given to us, we would do it. But it needs to be in a safe path.”

WHAT IS NEXT?

This conversation was the second of two photovoice-informed Micro Community Conversations. Taken together, the two cohorts now provide consumer-generated evidence from thirteen people with lived experience of cancer, across metropolitan, regional and rural Western Australia. The convergence between the groups is striking: two sets of people who had never met produced photographs of the same barriers using entirely different images.

Bringing the two conversations together

The priority is to synthesise the two datasets and to bring both groups together. Participants in this conversation viewed the first cohort's photographs during the group discussion and recognised their own experience in them immediately. A combined analysis will allow the project to distinguish barriers that are universal from those that are specific to regional and rural settings, to metastatic disease, or to particular points in the treatment pathway.

Putting the work in front of decision-makers

Participants were explicit that they want this material used, not archived. Work is underway with a researcher specialising in immersive arts practice to develop a way of showcasing the photographs and narratives to funders, policymakers and clinicians. How this is done will be shaped by participants themselves. Several have already indicated they are willing to speak directly to health professionals about their experience.

Feeding consumer priorities into funding applications

The material generated through this project is being used to shape a consumer-led research grant application, alongside related work on health service access, referral pathways and clinician training. Participants' own framing of the problem — that access has two parts, awareness and navigation — is the framing that application uses.

Workforce and pathway development

The findings in this report point clearly at two practical priorities. The first is training: participants encountered practitioners who were willing but not equipped for cancer-specific presentations, and in at least one case were harmed as a result. The second is co-location and continuity: exercise support that is delivered where treatment already happens, and that does not stop when treatment does. Both will be pursued with partner organisations, including cancer treatment providers and organisations working on exercise practitioner training.

ATTACHMENT 1. THE CONSUMER AND COMMUNITY INVOLVEMENT PROGRAM

The Consumer and Community Involvement Program (CCIProgram) is dedicated to embedding the voices of consumers and community members in health research. Established as part of the Western Australian Health Translation Network (WAHTN), the program works to ensure that research is shaped by lived experience and addresses real-world health challenges.

At the heart of the CCIProgram is a team committed to building connections between researchers, consumers and organisations. This team provides tailored support, guidance and resources to ensure consumer involvement is an integral part of research design, implementation and translation.

By championing consumer and community involvement at local, state and national levels, the CCIProgram continues to evolve, ensuring that health research is informed, shaped and guided by those with lived experience.

ATTACHMENT 2. WHAT IS A MICRO COMMUNITY CONVERSATION?

A Micro Community Conversation (MCC) is a structured, small-group discussion designed to gather in-depth insights from a select group of people with lived experience of a particular health issue. Typically involving four to six participants, an MCC provides a focused and intimate setting for researchers to engage directly with consumers, using a structured conversation format.

An MCC may be an ideal consumer involvement approach when:

- A particular health condition or research topic makes it difficult to engage a larger group, such as when the condition is rare or affects a highly specific population.
- The topic is sensitive, requiring a smaller, more supportive environment for participants to feel comfortable sharing their experiences.
- Researchers are in the early stages of exploring a topic and need initial insights before determining how best to expand consumer involvement.

Key insights from an MCC may be used to inform future studies or serve as a stepping stone toward a full Community Conversation where broader community input is sought.