

'It's just been hard work': Experiences of immune
checkpoint inhibitor treatments among people with
advanced cancer

Dr Tessa Watts, Reader in Supportive Care, Cardiff University
Dr Dominic Roche, Senior Lecturer Adult Nursing, Cardiff
University

Project Summary

Experiences of cancer immunotherapy with immune checkpoint inhibitors (ICI's).

- Three workstreams
 - WS1: Systematic review and qualitative evidence synthesis.
 - **WS2: Interview study (Patients' and families' experiences of ICI's).**
 - WS3: Interview study (Oncology health professionals' experiences with ICI's).

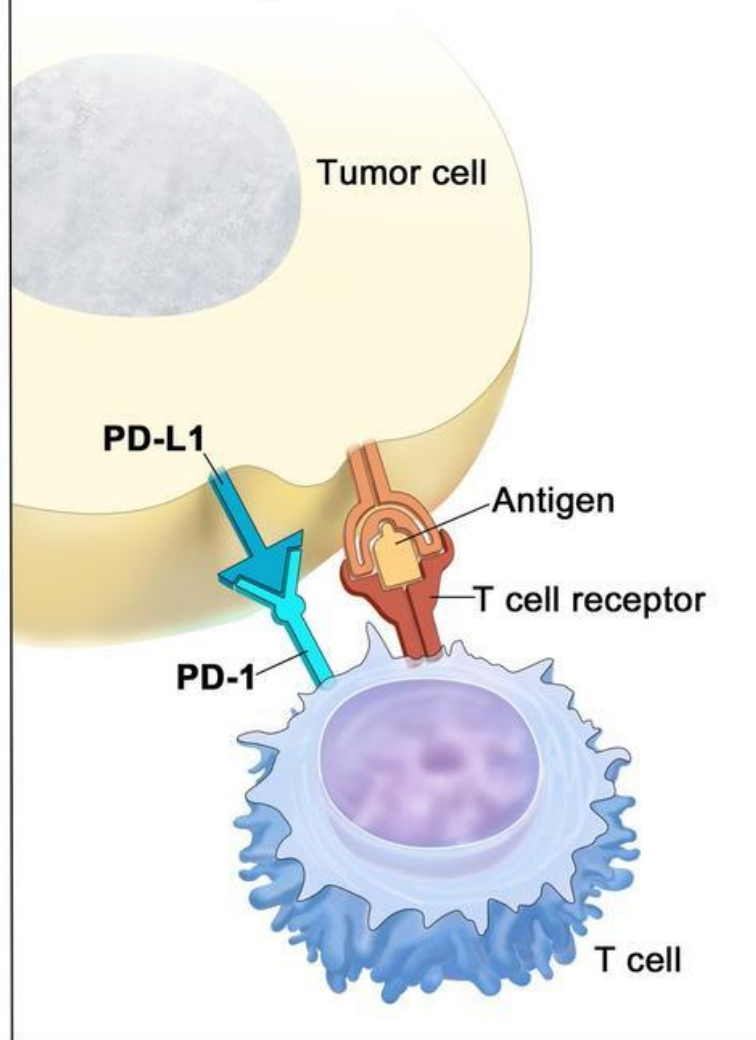
Aim

- This study aimed to explore and better understand ICI treatment experiences from the perspective of people with advanced cancers.
 - *To explore how people experience immune checkpoint inhibitor cancer immunotherapy treatment*
 - *To establish the expectations, concerns, information and support needs of people with cancer who are treated with immune checkpoint inhibitors.*

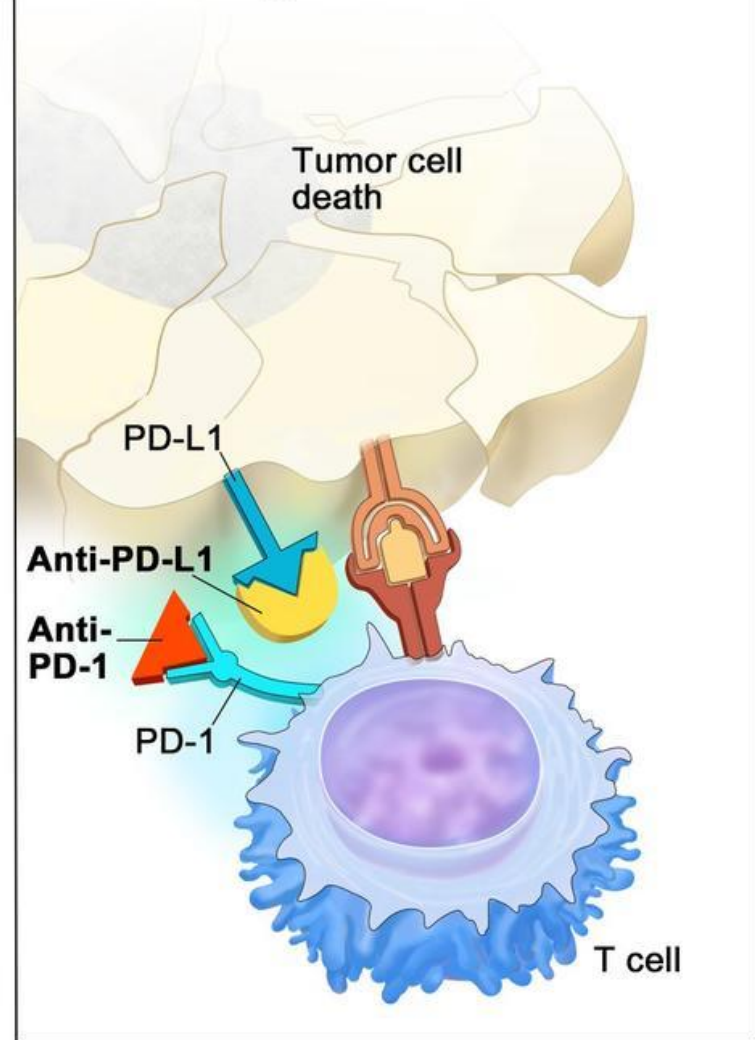
Background

- Clinical trials have demonstrated the benefits of immune checkpoint inhibitors (ICIs) for some people with advanced cancers.
- Earlier access to these treatments means more people will receive ICI's.
- Treatments can last for two years, and immune related adverse events (irAEs) may be experienced.
- IrAEs can be severe, challenging to manage and impact negatively on quality of life.
- *Yet, as research remains limited, we know little about people's experiences of ICI treatments and their associated supportive care needs.*

**PD-L1 binds to PD-1 and inhibits
T cell killing of tumor cell**



**Blocking PD-L1 or PD-1 allows
T cell killing of tumor cell**



A hand holding a silver pen writing on a colorful gel pen strip. The background is a blurred, colorful pattern of dots and lines, suggesting a gel pen strip or a similar artistic composition.

Methods

- Qualitative
- Purposive sample*
- In-depth interview
- Reflexive thematic analysis (Braun & Clarke)
- *Sixteen people with advanced melanoma (n=9), renal (n=4), and lung (n=3) cancer and two partners participated.*

Main Findings

- Participants were grateful for ICI treatment and oncology teams, particularly specialist nurses, were highly regarded. Participants also spoke about their experiences of information provision about the treatment.
- However, most participants felt unprepared for complex, lengthy, treatment surveillance and experienced ICI treatments as hard work.
- This work was entwined with emotions connected with existential ambiguity, and unmet information and support needs, often juxtaposed against irAEs.
- Support was derived from professionals, but participants also relied on their own social networks for this support

Participants
were grateful
for ICI
treatment and
oncology teams
were highly
regarded

- *I'm very grateful for what they've done. I can't remember who told me, but it's quite expensive, isn't it. (George, melanoma)*
- *It's just makes me feel quite confident, and, you know, I should be perfectly fit and healthy with it [immunotherapy]. (Derek, melanoma)*
- *They're on the ball and they know exactly what's happening, and I'm happy with that. (Harri, renal cancer)*
- *[I've] had a multi-disciplinary team looking at my case on a regular basis, I've got to say that I can't fault them. You know, it's been wonderful. [...] the care has been first class. (Andrew, melanoma)*
- *The nursing staff without fail have all been amazing, and if I have had any issues or if there's ever been any uncertainty or whatever, it's been fabulous. (Catrin, melanoma)*

Participants spoke about their experiences of information provided about their upcoming treatment

- *It was very good. It was [names CNS] who explained it all about the immune system, the immunotherapy would increase the immune system and it would fight... she had little diagrams there, it would attack the cancer cells and we were able to ask questions.” (George, melanoma, and Sara)*
- *I just don't want to know. I just want to get this treatment done and over with, and... You know, if something comes along, I'll face it then. I will look up the side effects. (Gwyneth, lung cancer)*
- *We certainly talked about the side effects, but not how long the treatment went on... was going to go on for. I thought it was maybe just a few weeks (...). From my research, I found out it's usually carried on for two years. (Steffan, lung cancer)*
- *[about treatment delivery] I didn't have a clue, to be quite frank. And they're all very good. They took me in and sat me down and said 'we've got to do this' and 'we're going put this in.' And they did explain to me what they were doing, [...]. (Mari, melanoma)*

Most participants felt unprepared for complex, lengthy treatment surveillance and experienced ICI treatment as *hard work*

- *I keep going with three monthly scans. I'm not quite sure how often I will get phone calls or contact with the consultant, but I know that, like, the clinical nurse did say she'd put me on her calling list for... it's a mandate, I guess. I don't know how often that would be; obviously, weeks... I didn't speak to them every week anyway, but maybe once a month, every couple of months, whatever, in between the scans. (Catrin, melanoma)*
- *When I've wanted to book bloods for my immunotherapy, I'd say I needed to ring about pre-chemo bloods because that's what they term them because nobody knows what immunotherapy is. Because they'd be, like, initially, "Oh, we can't fit you in," for whatever, and I'd have to say, "Look, I'm having my treatment on this day. I need my bloods on this day," and then miraculously they'd find me a slot. [...] **it's just been hard work.** (Catrin, melanoma)*
- *When I don't have to deal with the hospital things are fine, but as soon as I start dealing with the hospital about anything then it just... the thing is, it's all stress. I mean you don't... the situation I'm in I don't need any more stress. Anymore hassle because obviously that's not going to help the disease. (Rhys, lung cancer)*

This hard work
was intertwined
with emotions
connected with
existential
ambiguity, and
unmet
information and
support needs

- *It is a stressful time, but you think, well, don't get too down until you get the [scan] results, I try not to worry about it too much. (...). I have had the odd, little, tear when I've been on my own sometimes, when you feel a bit lonely and a bit down. (Gwyn, melanoma)*
- *I had a couple of scans and then had the results within a couple of days and then the next I know, I asked, 'will we get the scan results next week,' 'oh no,' it's about three weeks we're getting scan results. (Rhys, lung cancer)*
- *I'm due a scan now coming up. (...) I think you just get really, really nervous about having... especially now at the moment, this could be the one where he says to me, "Well, we can't see any disease, you know, we'll just monitor you and keep you on the treatment." Or "it's come back with a vengeance." It's always going to be one or the other. Never going to be as straightforward as you think. (Evan, renal cancer)*
- *[I've had] three scans and the blood tests. He's [consultant] onto me straightaway, telling me the results and reassuring me with the shrinking of the cancer. He's over the moon and I'm over the moon. He keeps me really informed and he actually rung me up one day and said (...) 'I'm chuffed to rockets,' he said, 'Your cancer's reduced dramatically again.' I thought it was wonderful. (...). It lifted me way up. (Harri, renal cancer)*

The hard work associated with ICI treatment was also often juxtaposed against irAEs

- *I suppose there's not enough knowledge around it [immunotherapy] I suppose at a, local, sort of, GP level. (Catrin, melanoma)*
- *I could hardly eat and drink. I just didn't want it, I couldn't keep it down, I would bring it back up if I ate something. That went on for a couple of weeks. We went to see our local doctor and they give me all sorts of stuff to try including food type drink to have. But still my appetite was totally gone. And in the end, we phoned the consultants people at the hospital, and they said, you got to go to A&E this afternoon (...) I was in the A&E department for a day, then I was moved onto a ward and was continually fed these drips. Lot of doctors were coming in looking at me and talking and asking what was going on, how I felt, and trying to find the cause of it. It seems as though they didn't understand the immune therapy I was on. (...) it wasn't until a specialist nurse come round following my report that I was coming into hospital, they come and found me in the A&E department and then started speaking to the doctors and I do believe explaining what the immune therapy was all about. (Gryff, renal cancer)*

Support was derived from professionals, but participants also relied on their own social networks for this support.

- *They [oncology team] were very, very supportive, they were. They were really good. [names oncologist] was very, very reassuring. [names site specific CNS]. I can't fault [names site specific clinical nurse specialist] at all. I've got no fault with her at all because she's really good as well. She's helped me through a lot as well. (Dewi, melanoma)*
- *I was on this trolley in A&E, amongst a lot of other people, and this specialist nurse come in and was reading through my notes, come over to speak to me and explained that they were from the Marie Curie nurses who are in the hospital. (...) And asked me how I was, what were the effects were. And said, 'well, I'll go and have a chat with the doctors' and come... 'we'll come back to you.' Within a couple of hours, a doctor had come down into the A&E department and wrote the prescription out for some drugs to give me. Then this specialist nurse come back and explained that there was a problem with my thyroid gland, that the treatment had knocked the thyroid gland out (...). (Gryff, renal cancer)*
- *I phoned up the helpline, and they said they'd put it through to the Nurse or they'll get the Nurse to ring me back and I've gone through pretty quick every time they said they'd go through to the Nurse. Or if they said the Nurse would phone me back it's been within the half hour... So, it's been pretty good like, the helpline. (Dewi, melanoma)*

Support was derived from professionals, but participants also relied on their own social networks for this support.

- *Benefits wise, money wise, [names person] has been amazing, again based with the Macmillan, she's been sorting everything out, my PIP and all that. Because I did go back to work, so I went off ESA and then had to go back on it. Work just didn't work out, basically. (Evan, renal cancer)*
- *Two of my closest friends they died of cancer and their wives are very supportive, they ask me, and then if there's anything that twinkles in their memory, they tell me about their husbands and so I get comfort, I get thing from my own circle type of thing. (Ralph, renal cancer]*
- *I'm a very strong and self-contained person. I've got my wife and my family close by anyway. And I've got a circle of good friends, intelligent people who would help and support if I needed any. (David, melanoma)*

Discussion & Conclusions

- This study offers new insights into how ICI treatments are experienced by people affected by advanced cancers.
- Findings signal the need for innovative, co-developed supportive resources and interventions implemented at discrete points across the ICI treatment pathway, together with truly person-centred services to minimise burdens and enhance patients' experiences.

Recommendations for Practice

- Investment in the development, and appropriately implemented, theoretically underpinned, multi-dimensional co-produced immune checkpoint inhibitor patient education is needed.
- Consideration should be given to creating opportunities for patients to be actively engaged in the co-production of immune checkpoint inhibitor patient education resources.
- Enhanced self-management patient education is needed to ensure informed, activated patients.

Acknowledgements

We would like to thank:

- Macmillan Cancer Support for funding this project;
- The core research team
 - Ms. Janet Bower, Hywel Dda University Health Board
 - Dr Alison Brewster, Swansea Bay University Health Board/ Hywel Dda University Health Board
 - Mr. John Buckman our PPI representative
 - Professor Emirata Debbie Fenlon, Swansea University
 - Professor Deb Fitzsimmons, Swansea University
 - Dr Stephen Jennings, University of Bristol
 - Dr Sally Anstey, Reader Emirata, Cardiff University
 - Dr Judit Csontos, Cardiff University
- The Project Steering Group chaired by Professor Paul Gill

Thank you for listening

Are there any questions?