Measuring What Matters: Raising the Standard for Follow-Up After Cancer

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Company Name	*Honoraria/ Expenses*	*Consulting/ Advisory Board*	*Funded Research*	*Royalties/ Patent*	*Stock Options*	*Ownership/ Equity Position*	*Employee*	*Other (please specify)*
AstraZeneca	x	x						
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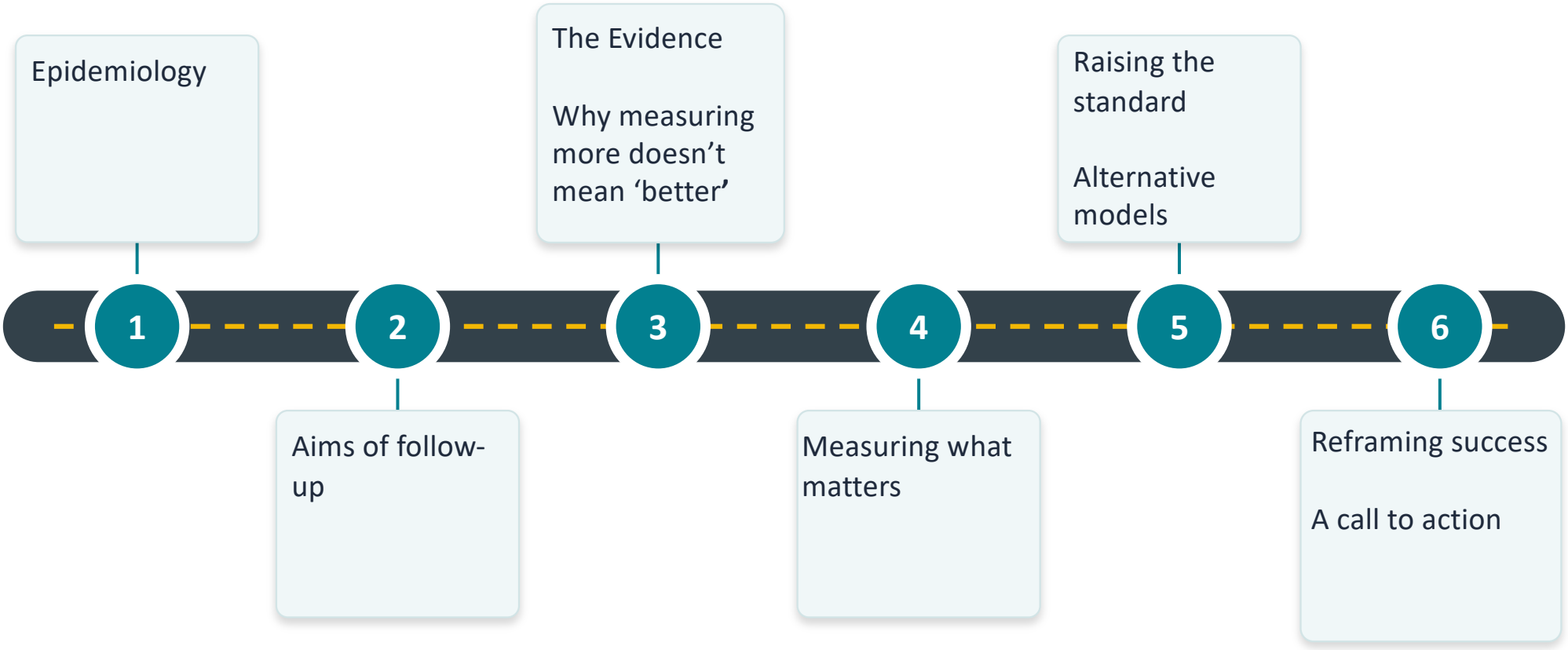
Reliis Ltd					x			
ANZGOG			x					Non-renumerated, Director and Chair Research Advisory Committee
IGCS								Non-renumerated, Director and Chair Education Committee
Cancer Council Australia								Non-renumerated, Cervical Cancer Treatment Guidelines Working Party

Disclosures

Presentation Outline



Take Home Messages

1. Follow-up is least examined component of cancer care
2. We have been measuring success by the wrong yardstick
3. Areas for improvement: ‘where’ and ‘how’ & what we measure
4. Not one size fits all

THE BOTTOM LINE

Survivorship care fails not for lack of intent but for lack of capacity

Epidemiology

169,759

Estimated number of cancer cases diagnosed in 2025

53,545

Estimated number of deaths from cancer in 2025

71.6%

Chance of surviving at least 5 years (2017-2021)

527,711

People living with cancer at the end of 2021 (diagnosed in the 5-year period 2017 to 2021)

https://www.canceraustralia.gov.au/research-grants/data-and-statistics/cancer-australia-statistics

Epidemiology

- Australia
  - > 1 million people living with cancer/had cancer in the past 40 years
- Globally
  - Nearly 54 million people living with a cancer diagnosed in past 5 years

AIHW 2023. https://www.aihw.gov.au/reports/cancer/cancer-data-in-australia/contents/about
Luo Q et al. The Lancet Public Health. 2022;7(6):e537-e548
https://canceratlas.cancer.org/burden-of-cancer/cancer-survivorship/

Epidemiology

- Queensland data linkage study 2013-2016, cohort of 230,380 people
- Cumulative mean annual healthcare expenditure was AU$3.66 billion
- Highest costs
  - Prostate (AU$538 m), Breast (AU$496 m), Colorectal (AU$476 m) cancers
- Costs highest in the first year after diagnosis and decrease over time

Merollini KMD et al. In J Environ Res Public Health 2022 Aug 2;19(15):9473

Aims of follow-up after curative intent treatment

1. Identify and manage late side effects of treatment
2. Diagnose recurrence
3. Identify and manage significant psychosocial symptoms
4. Measure how we're performing

THE BOTTOM LINE

The focus in the oncology clinic has been on diagnosing recurrence

More is not always better

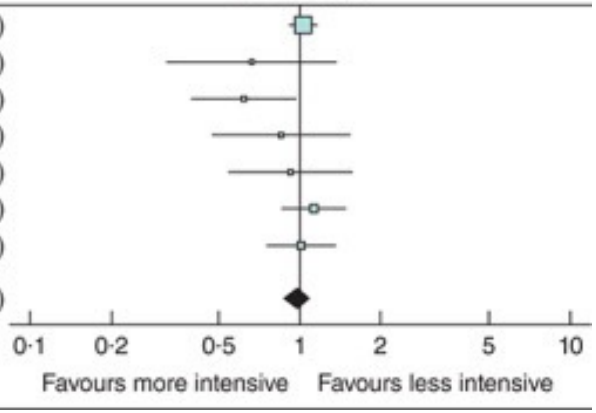
1. Earlier detection sounds beneficial
2. Intensifying surveillance changes timing of detection but not survival
3. In many cancers more scans, visits, & tests increase burden without long-term benefit
4. Costs – anxiety, false positives, healthcare costs

More is not always better

- In colorectal cancer intensive vs routine follow-up results in
  - Earlier diagnosis of recurrence by median of 10 months (IQR 5 – 24 months)
  - No detectable overall survival advantage

Reference	log[hazard ratio](s.e.)	More intensive	Less intensive	Weight (%)	Hazard ratio
CEASL[30]	0·03(0·06)	108	108	50·3	1·03 (0·92, 1·16)
Ohlsson *et al.*[17]	−0·41(0·37)	53	54	2·8	0·66 (0·32, 1·37)
Pietra *et al.*[22]	−0·48(0·23)	104	103	6·8	0·62 (0·39, 0·97)
Mäkelä *et al.*[16]	−0·16(0·3)	52	54	4·1	0·85 (0·47, 1·53)
Rodriguez-Moranta *et al.*[2]	−0·08(0·27)	127	132	5·0	0·92 (0·54, 1·57)
GILDA[4]	0·12(0·14)	615	613	16·4	1·13 (0·86, 1·48)
FACS[3]	0·01(0·15)	901	301	14·6	1·01 (0·75, 1·36)
Total		1960	1365	100·0	0·98 (0·87, 1·11)

Heterogeneity: $\tau^2 = 0{\cdot}00$; $\chi^2 = 6{\cdot}94$, 6 d.f., $P = 0{\cdot}33$; $I^2 = 14\%$
Test for overall effect: $Z = 0{\cdot}30$, $P = 0{\cdot}77$



Mokhles S, Br J Surg. 2016 Aug 4;103(10):1259–1268

More is not always better

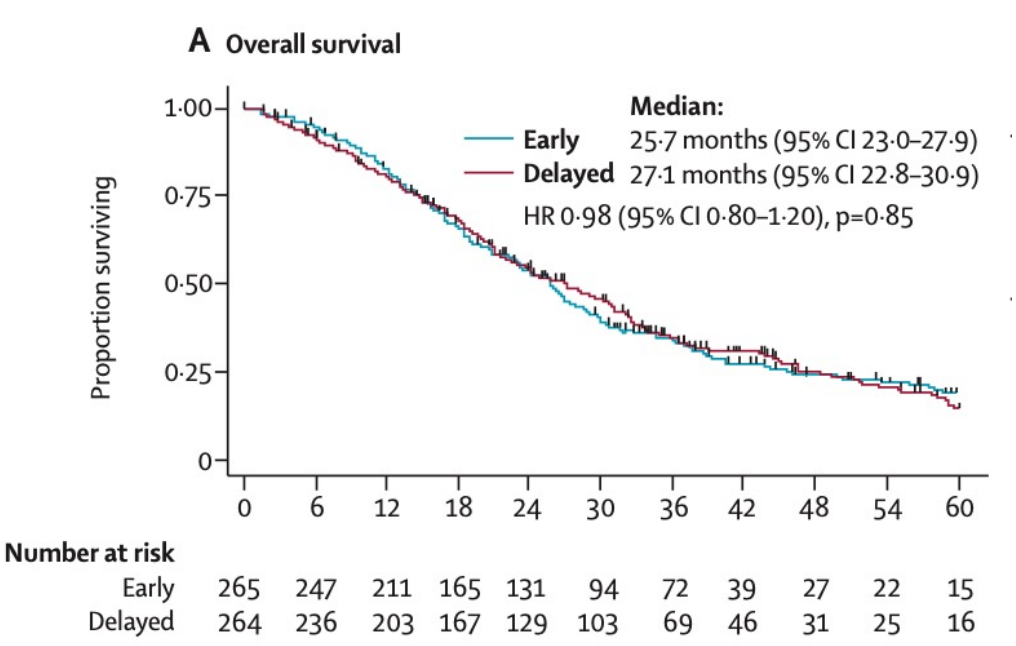
	OS			CSS	
Cancer type	*N*	*HR [95% CI]*	I^2	*N*	*HR [95% CI]*
All studies					
Colorectal	30	0.82 [0.73–0.91][a]	85%	11	0.80 [0.63–1.01]
Lung	12	0.94 [0.84–1.05]	49%	1	1.45 [0.84–2.5]
Breast	8	0.80 [0.54–1.18]	92%	3	0.52 [0.27–1.02]
Upper GI	5	0.79 [0.66–0.95][a]	0%		–
Prostate	1	1.00 [0.86–1.16]	NA		–

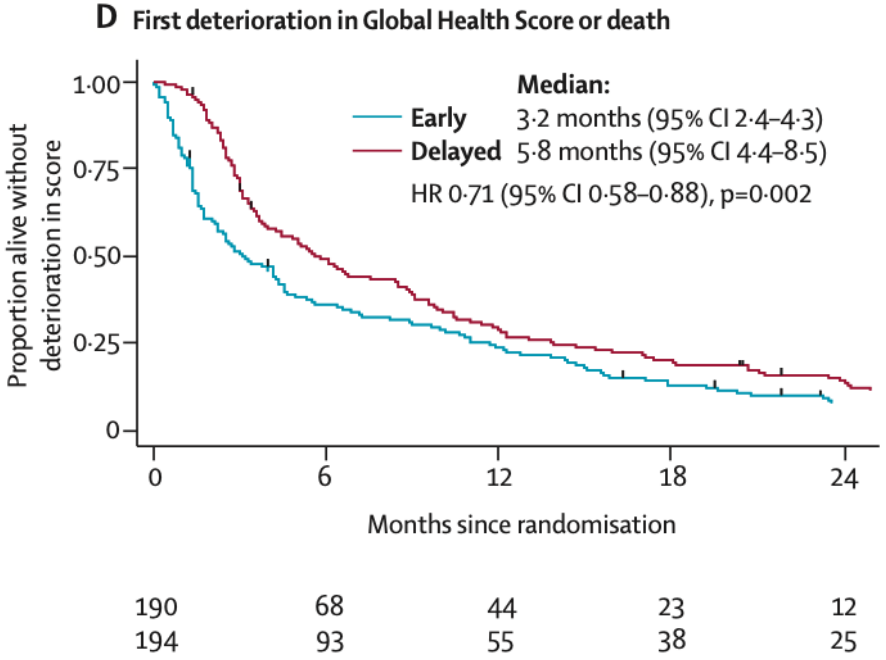
Galjart B et al. European Journal of Cancer, 2022; 174, 185-199

More is not always better

Rustin G. et al. Lancet 2010 Oct 2;376(9747):1155-63.

More is not always better





Rustin G. et al. Lancet 2010 Oct 2;376(9747):1155-63.

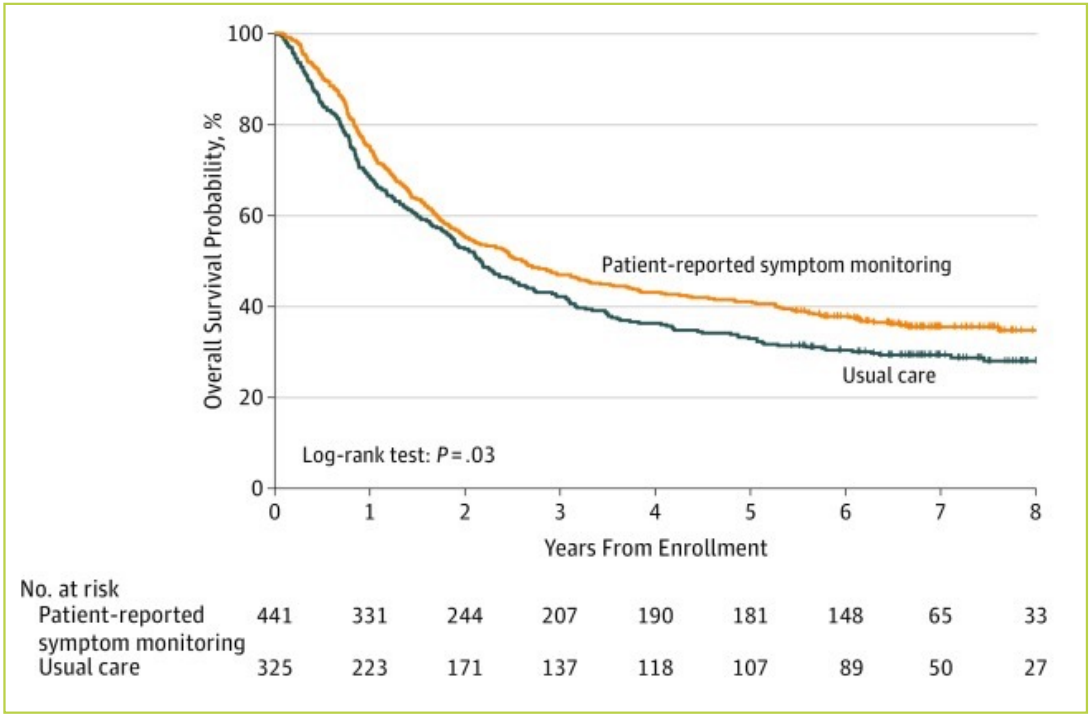
More is not always better

- Caveats with interpretation of the findings of Rustin et al.
  - Secondary cytoreduction surgery at first recurrence
  - Maintenance therapies – Bevacizumab and PARPi

- Uncertain if the findings are applicable today

What matters to patients

- The needs of individuals living with cancer are highly personal
- What patients value encompasses their beliefs, priorities, and expectations
- PROMs and PREMs have been widely developed and validated
- These tools have demonstrated benefits, including improved symptom management, enhanced quality of life (QoL), and even reduced mortality



- 766 patients starting chemotherapy
- Randomised to PROs vs routine care
- Primary outcome change in HRQOL at 6 months
- Post-hoc analysis of overall survival

- PRO group median OS was 31.2 months
- Usual care median OS was 26.0 months
- 5-month difference (*P* = .03)
- HRQOL improved in 34% in PRO group vs 18%
- HRQOL worsened among fewer in PRO group
- (38% v 53%; *P* = .001).

Basch E. et al JAMA 2017 Jun 4;318(2):197–198

What We Measure Misses What Matters

We optimise what we measure — yet the PRO tools in routine use omit many items that matter to patients

Instrument	Financial toxicity	Sexual function
EORTC QLQ-C30	1 item only	Not captured
FACT-G	Not captured	Not captured
EQ-5D	Not captured	Not captured
PROMIS-29 / SF-36	Not captured	Not captured
PRO-CTCAE	Not captured	Captured

PROMIS includes a sexual-function item bank (SexFS), but routine short forms omit it.

WHAT FILLS THE GAP

Financial toxicity
COST / FACIT-COST

Sexual function
FSFI · EORTC SHQ-22

Dedicated tools — rarely part of routine follow-up.

Lefkovits *et al. BMC Health Services Research* (2024) 24:778
https://doi.org/10.1186/s12913-024-11042-8

BMC Health Services Research

REVIEW Open Access

Incorporating patient-reported outcome measures (PROMs) into a clinical quality registry (CQR) for ovarian cancer: considerations and challenges

Yael R Lefkovits[1,2,3*], Natalie Heriot[2], Alice Sporik[2], Sharnel Perera[2], Michael Friedlander[4], Cyril Dixon[5], Paul A Cohen[6,7,8], Yeh Chen Lee[9,10,11], Simon Hyde[12], Gary Richardson[13], Penelope Webb[14], Robert Rome[15], Madeleine King[16], John Zalcberg[2] and Penelope Schofield[3,17,18,19]

What matters to patients

- PROMs quantify patient health outcomes
- PREMs describe patient experience of care
- Patient values are the personal significance patients attribute to experiences and outcomes
- PRMs do not often incorporate patient values

We need to co-design tools and frameworks that reflect patient values

Measuring Is Not the Same as Caring

Beyond the instrument lie two failures: no capacity to respond, and no reach to those who need it most.

Measurement without response is theatre

- Every PROM collected creates an obligation to act on it
- Alert fatigue — and who actually closes the loop?
- Survivorship deliverables are crowded out by acute demand

Not *'can we measure it?'* but *'have we resourced anyone to respond?'*

Who the method renders invisible

- Digital divide, language, health literacy, age, rural & remote access — acute across WA
- An app in English reaches those with the least unmet need, and misses those with the most

Measurement can entrench inequity while appearing to address it.

Evaluating consumer satisfaction with the King Edward Memorial Hospital Gynaecological Cancer Survivorship Clinic

Natalie Williams[1,2], Lisa Barr[1], Georgia Griffin[1,2], Ella Burton[1], Emma Allanson[1,3], Paul Cohen[1,3]

[1]King Edward Memorial Hospital; [2]Curtin University; [3]University of Western Australia

BACKGROUND

Approximately 430 Western Australians are diagnosed with a gynaecological cancer every year. The Survivorship Clinic is a new model of care for people following primary treatment for gynaecological cancers. It combines a strong multidisciplinary team approach with individualised survivorship care planning.

PROJECT AIM

To evaluate the King Edward Memorial Hospital (KEMH) Survivorship Clinic and patient satisfaction with the service, since its inception in July 2024.

METHODS

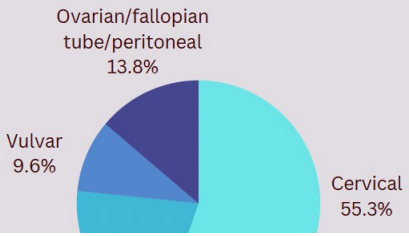
Phase one → Retrospective audit of all clinic patients between July 2024 and May 2025
Phase two → Online patient satisfaction survey between August and November 2025

"This was the best thing I have had the opportunity to do since my first diagnosis" (P11)

PATIENT CHARACTERISTICS

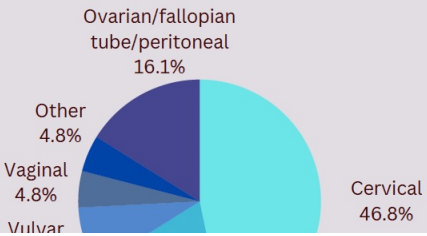
Of 101 patients **audited**:

- 100% of female gender
- 68.5% resided in a metropolitan location
- 55.4% born in Australian born
- 5% identified as Aboriginal Australians
- 16 different cultural backgrounds



Of 53 patients **surveyed**:

- 5% identified as Aboriginal Australians
- 71.7% described their cultural background as Australian
- 96.2% preferred health information delivered in English



Gynaecologic Oncology Survivorship Clinic July 2024 – June 2026

- 175 patients; 419 clinic visits
- 287/419 (68.5%) visits had at least one PROM completed
- 34/419 (8.1%) patient visits completed all 6 PROMs
- 249/419 (59.4%) visits had 4–6 PROMs completed

More is not always better

1. *"The paperwork being filled in at every visit. Maybe a short form to see if anything has changed."*
2. Questionnaires miss some aspects of HRQOL as not sufficiently nuanced
3. Some questions are triggering and re-traumatise patients

One third of patients did not complete a single PROM

Models that may raise the standard

- Patient Initiated Follow-Up (PIFU)
- Nurse-led follow-up
- Remote electronic PRO-based symptom monitoring
- ctDNA/molecular residual disease-guided surveillance

Models that may raise the standard

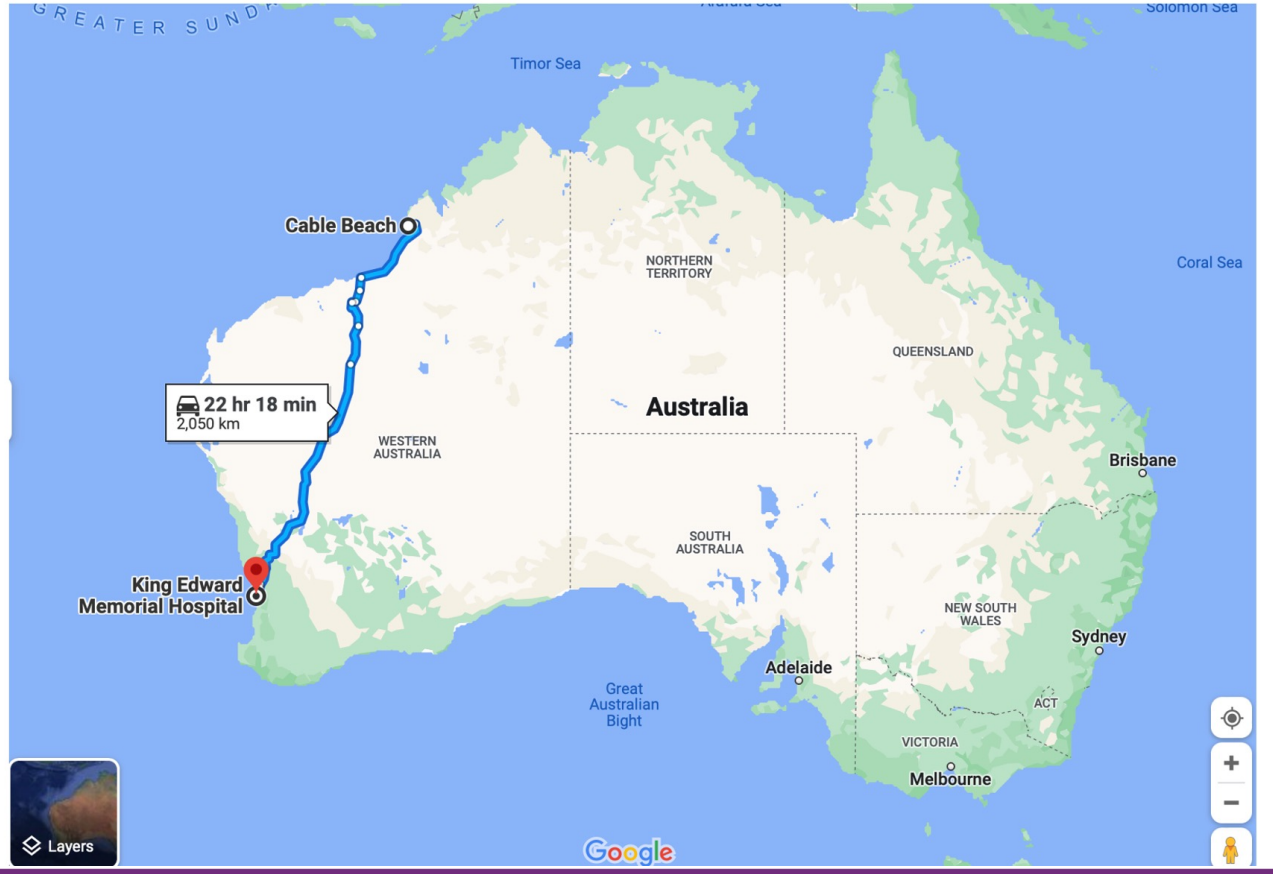
- Patient Initiated Follow-Up (PIFU)
- Systematic review that included eight studies
- Four cancer types (breast, colorectal, endometrial, prostate)
- Findings:
  - No difference in HRQOL
  - PIFU cheaper
  - Fear of recurrence higher in one study in PIFU group
- Studies not powered to evaluate survival or recurrence rates

Newton C. et al. Fron Oncol. 2022 Oct 13:12:954854

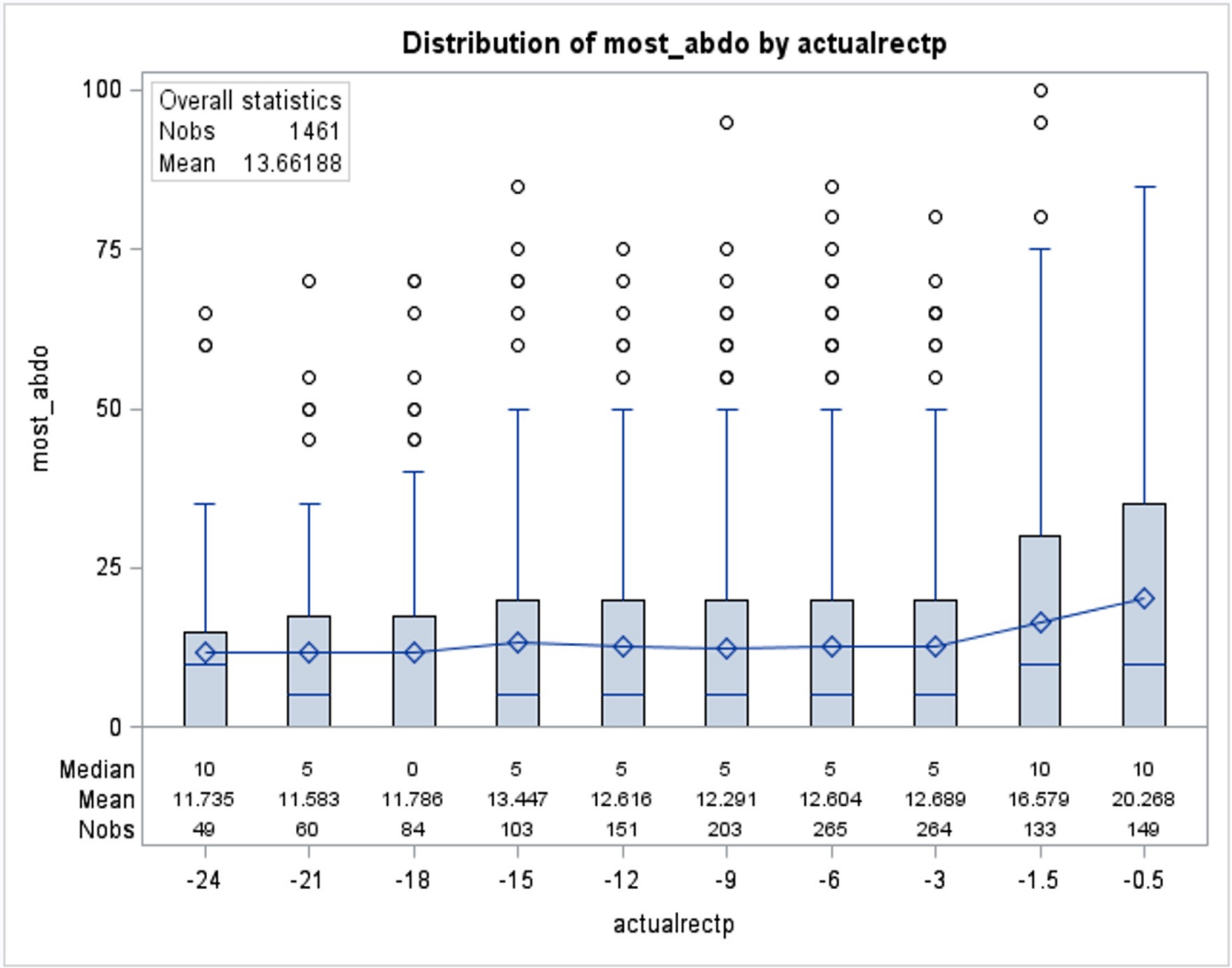
Models that may raise the standard

- Nurse-led follow-up


KING EDWARD
MEMORIAL HOSPITAL


Timor Sea
Coral Sea
Cable Beach
22 hr 18 min
2,050 km
NORTHERN TERRITORY
QUEENSLAND
Australia
WESTERN AUSTRALIA
SOUTH AUSTRALIA
NEW SOUTH WALES
Brisbane
Sydney
Adelaide
Great Australian Bight
ACT
VICTORIA
Melbourne
King Edward Memorial Hospital
Layers
Google

Most-Abdo Scores by Time Prior to Recurrence



Clinical trial

Getting the MOST out of follow-up: a randomized controlled trial comparing 3 monthly nurse led follow-up via telehealth, including monitoring CA125 and patient reported outcomes using the MOST (Measure of Ovarian Symptoms and Treatment concerns) with routine clinic based or telehealth follow-up, after completion of first line chemotherapy in patients with epithelial ovarian cancer

Paul A Cohen [1,2,3] Penelope M Webb,[4] Madeleine King,[5] Andreas Obermair,[6] Val Gebski,[7] Phyllis Butow,[8,9] Rachael Morton,[7] Wanda Lawson,[10] Patsy Yates,[11] Rachel Campbell,[5] Tarek Meniawy,[12] Michelle McMullen,[12] Andrew Dean,[13] Jeffrey Goh,[14,15] Orla McNally,[16,17] Linda Mileshkin,[18,19] Philip Beale,[20] Rhonda Beach,[10] Jane Hill,[21] Cyril Dixon,[21] Sue Hegarty,[21] Jim Codde,[3] Angela Ives,[22] Yeh Chen Lee,[23,24] Alison Brand,[25,26] Anne Mellon,[27] Sanela Bilic,[1] Isobel Black,[1] Stephanie Jeffares,[1] Michael Friedlander [23,28]

Int J Gynecol Cancer. 2022 Apr 4;32(4):560-565.

BERLIN 2025 ESMO congress

A Phase II randomized trial of nurse led telehealth follow-up including patient reported outcomes using the MOST (Measure of Ovarian Symptoms and Treatment Concerns) vs routine clinic based or telehealth follow-up after completion of chemotherapy in patients with ovarian cancer

P.A. Cohen, A. Obermair, V. Gebski, M.T. King, P. Butow, R. Campbell, S. Bilic, A. Brand, J. Codde, J. Goh, A. Ives, A. Kiberu, W. Lawson, A. Mellon, O. McNally, T. Meniawy, L. Mileshkin, R. Morton, P. Webb, M. Friedlander

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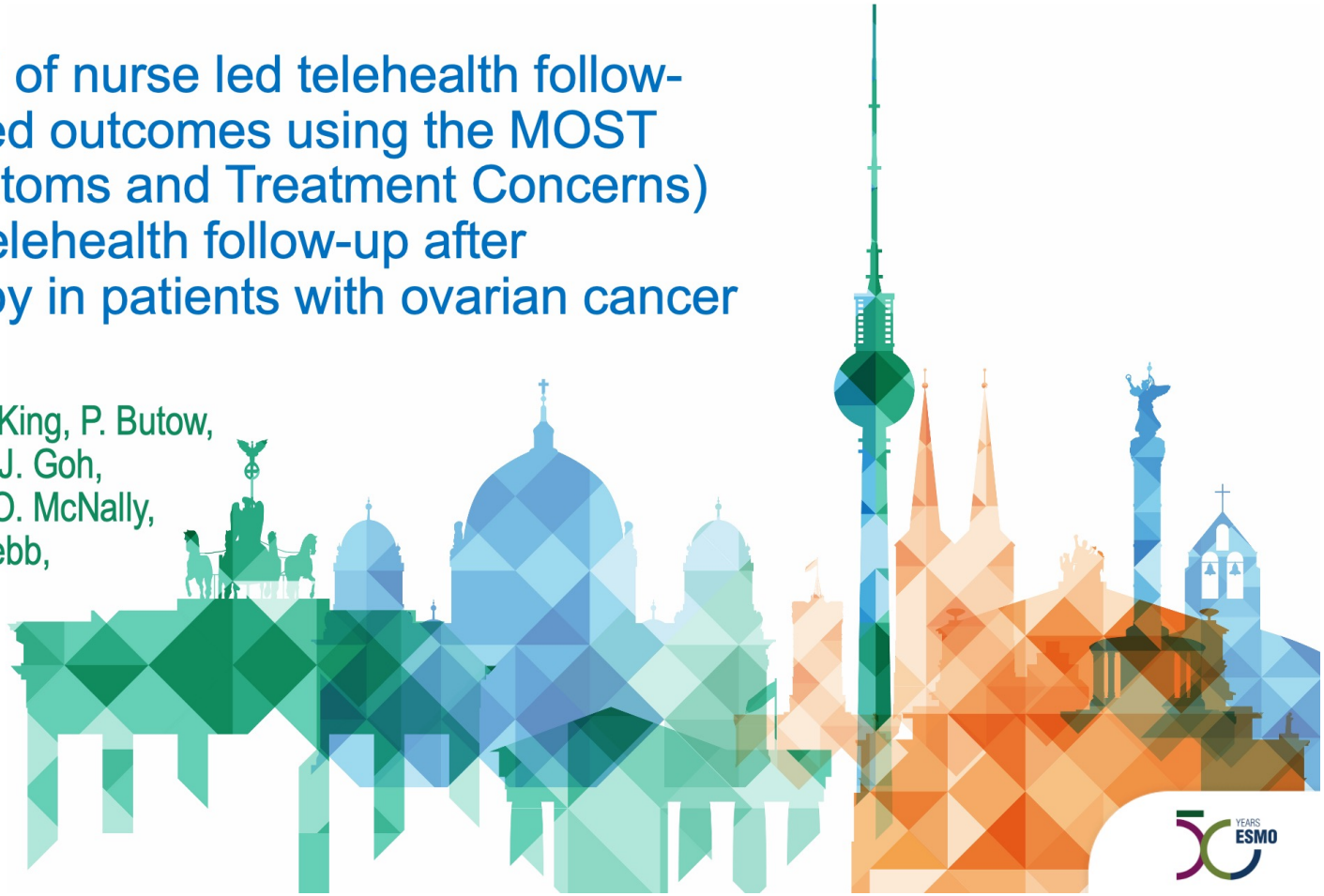


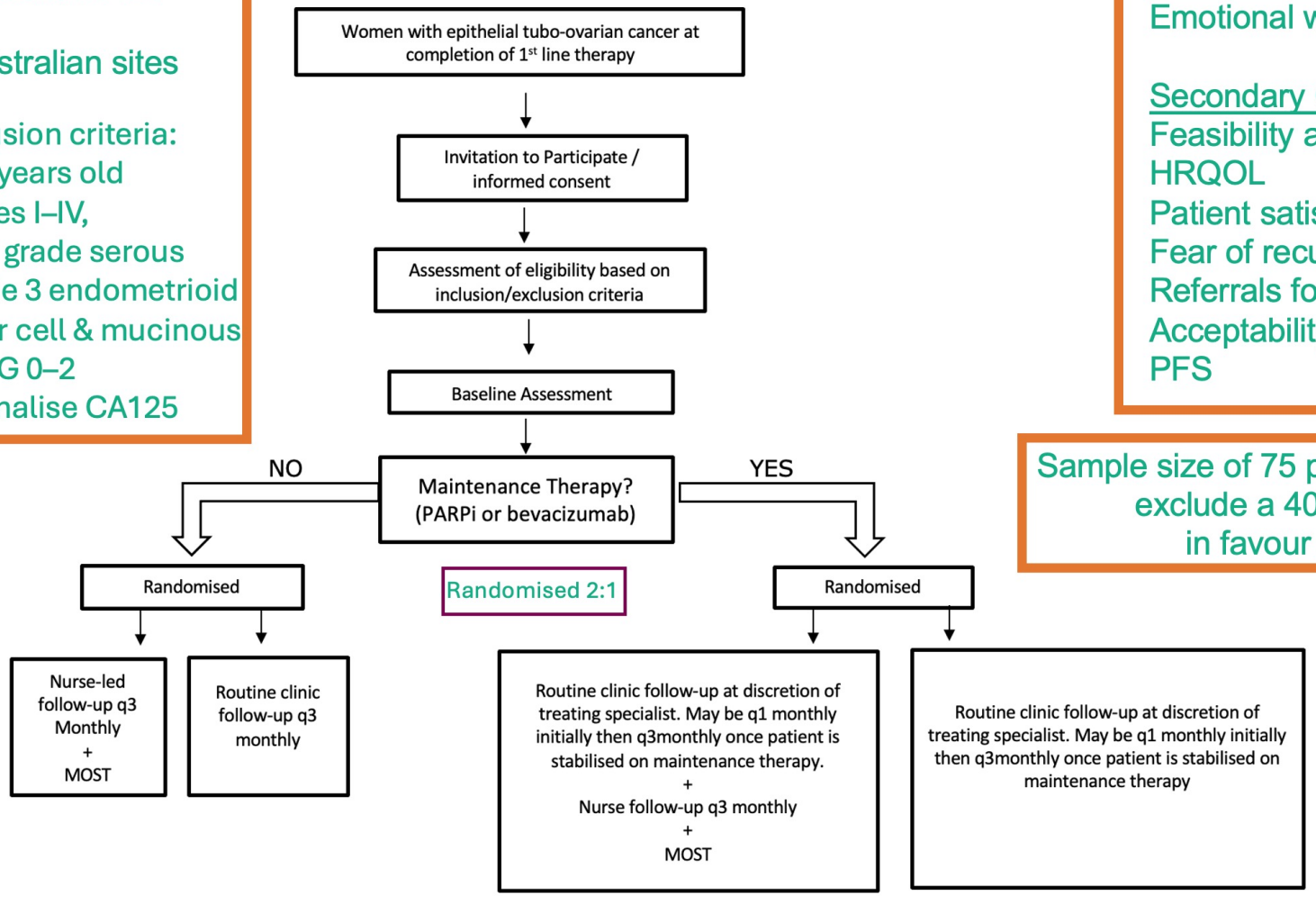
19 October 2025

STUDY SCHEMA

Multicentre RCT

6 Australian sites

Inclusion criteria:
≥18 years old
Stages I–IV,
High grade serous
Grade 3 endometrioid
Clear cell & mucinous
ECOG 0–2
Normalise CA125



Primary Outcome
Emotional well being (EWB) at 6 months

Secondary Outcomes
Feasibility and safety
HRQOL
Patient satisfaction
Fear of recurrence
Referrals for symptom management
Acceptability
PFS

Sample size of 75 patients has 80% power to exclude a 40% rate of low EWB in favour of a rate of 25%

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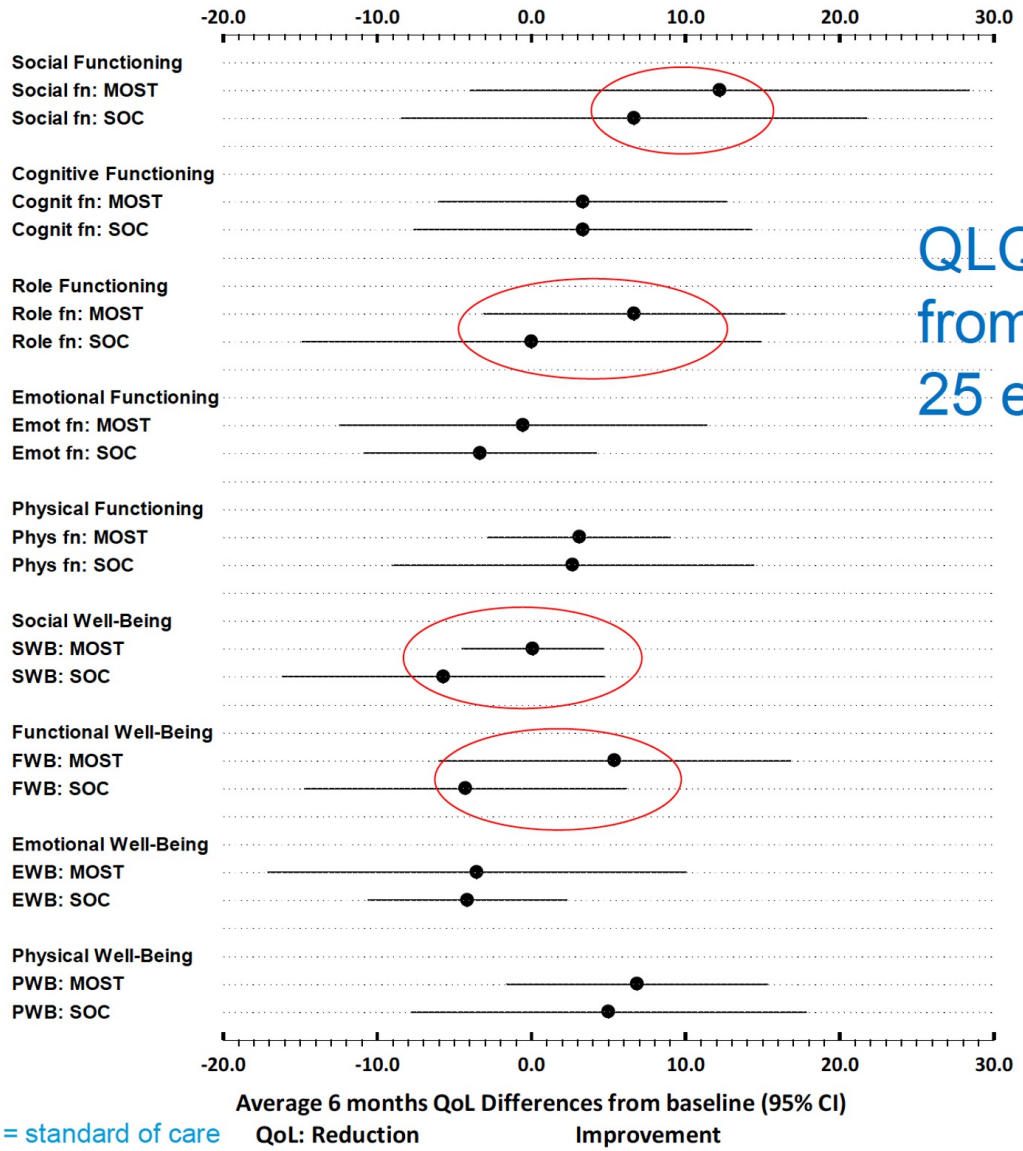
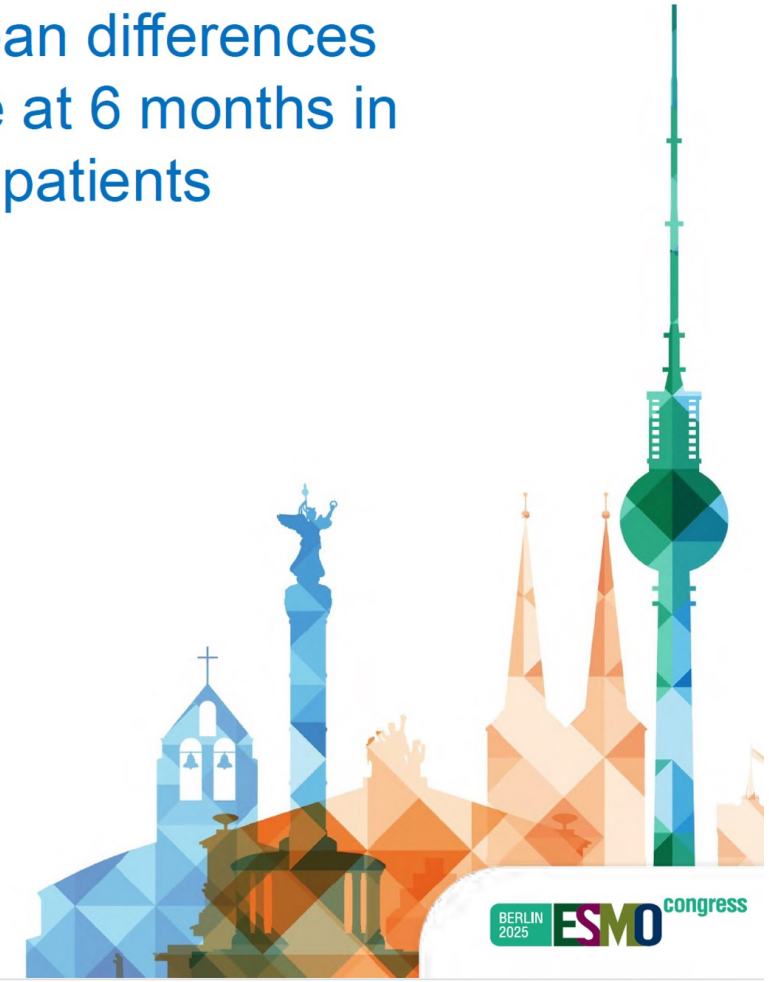
Results - QOL

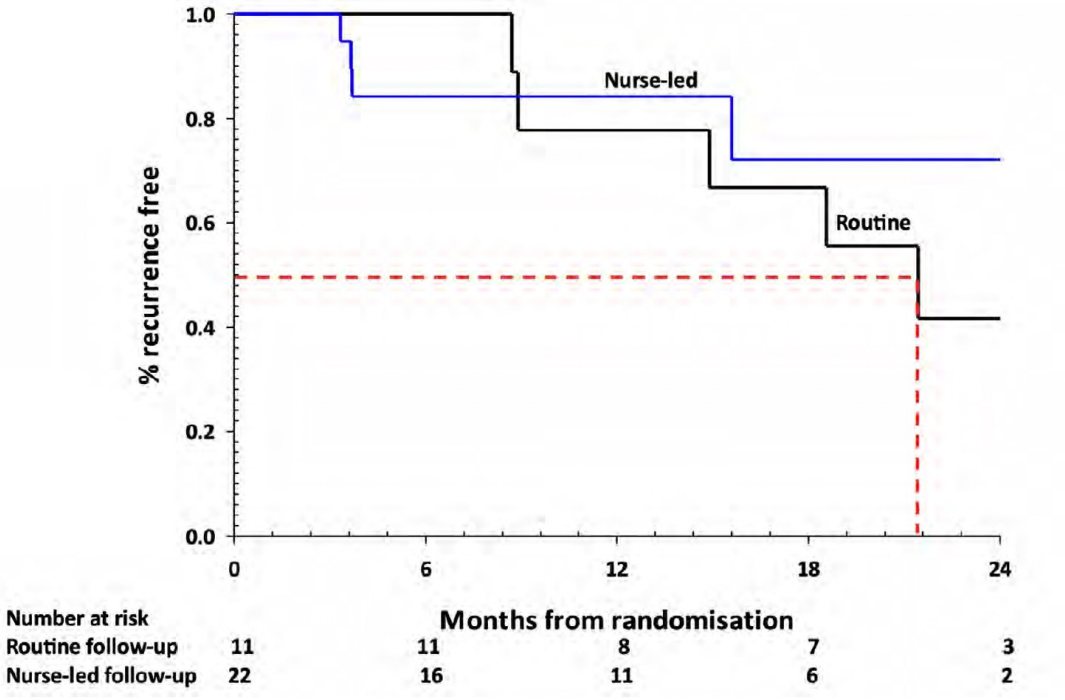
QLQ-C30 mean differences from baseline at 6 months in 25 evaluable patients



SOC = standard of care



Results – Recurrence-Free Survival



	Routine care	Nurse-led
Median		
Follow- up time	18 months	
Time to recurrence	21.4 months	Not reached
Risk of recurrence/month (%)	2.8 [CI: 1.2-6.8]	1.6 [CI:0.6-4,2]
Hazard ratio	0.63 [CI:.0.17-,2,36]	

Paul A. Cohen FRANZCOG MD

Results - Referrals

Referrals to Health Services	Nurse led follow-up (n = 22) n (%)	Routine care (n = 11) n (%)
Clinical Psychologist	5 (2.7)	0 (0.0)
Sexual Counsellor	1 (4.5)	0 (0.0)
Dietician	2 (9.0)	0 (0.0)
Physiotherapist	4 (18.2)	0 (0.0)
Occupational Health	4 (18.2)	0 (0.0)
Total	**16 (72.7)**	**0 (0.0)**

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Results – Patient Satisfaction

Journal of Clinical Oncology
An American Society of Clinical Oncology Journal

Meeting Abstract: 2025 ASCO Annual Meeting I

FREE ACCESS | Symptom Science and Palliative Care | May 28, 2025

"The telehealth means I get distance from the hospital so I don't feel so much like a patient": A qualitative sub-study examining the acceptability of nurse-led follow-up for ovarian cancer via telehealth using the MOST-S26 to structure consultations.

Authors: Rachel Campbell, Megan Jeon, Michael Friedlander, Madeleine T. King, Andreas Obermair, Sanela Bilic, Alison Brand, ... SHOW ALL ... , and Paul Andrew Cohen | AUTHORS INFO & AFFILIATIONS

Publication: Journal of Clinical Oncology • Volume 43, Number 16_suppl
https://doi.org/10.1200/JCO.2025.43.16_suppl.12099

Results: 3 Overarching Themes

Participants = 14 women with OC (P); 6 study nurses (H)

Key Patient-Centred Benefits

- Convenience and flexibility
- Provides a sense of feeling cared for
- Enables personalised, holistic care and prompt symptom management
- Provides dedicated space for patients to freely express experiences and emotions

"I just haven't been abandoned after going through treatment. That's a nice thing to have that connection" (P1)

Challenges to delivery from nurses' perspectives

- Lack of clear referral pathways for troublesome symptoms
- Inability to observe physical cues to inform care
- Difficulties establishing rapport
- Emotional impact on nurses when patients experience recurrence
- Not suitable for all patients (e.g. non-English speaking or low literacy)

"It does make it harder to get that rapport sometimes when you can't see them face to face." (H6)

Usefulness of MOST-S26 to support consultations

Nurses reported MOST-S26 provides a useful tool to guide consultations and referrals; detect early signs of recurrence; track symptoms over time and flag symptoms for discussion; and help patients' reflect on their symptoms

"[MOST-S26] does give some structure to your consult and f... on symptoms that are important and a problem to them." (

Paul A. Cohen FRANZCOG MD

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Prof. Madeleine King
Prof. Phyllis Butow
Prof. Rachel Morton
Dr. Rachel Campbell
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Ms. Anne Mellon
Prof. Penelope Webb
Prof. Andreas Obermair
Ms. Wanda Lawson
Prof. Patsy Yates
A/Prof. Jeffrey Goh
Prof. Jim Codde
A/Prof Tarek Meniawy,
Dr Andrew Kiberu
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Trial Coordinating Centre

St John of God Subiaco Hospital

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Mr. Dino Cercarelli
Ms. Taryn Quartermaine
Ms. Stephanie Jeffares
Ms. Isobel Black

Locally Advanced Cervical Cancer Adjuvant Setting - ctDNA

ESMO GOOD SCIENCE BETTER MEDICINE BEST PRACTICE

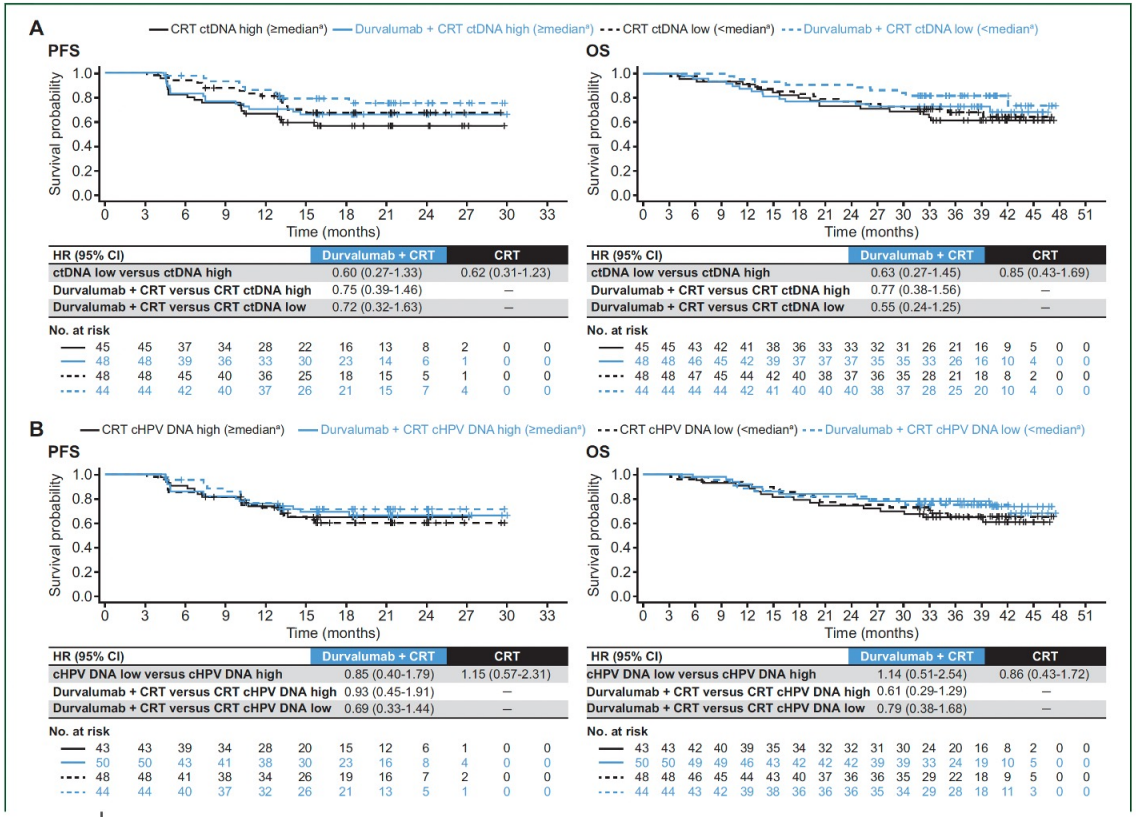
ANNALS OF ONCOLOGY DRIVING INNOVATION IN ONCOLOGY

ORIGINAL ARTICLE

Ultrasensitive detection and tracking of circulating tumor DNA to predict relapse and survival in patients with locally advanced cervical cancer: phase III CALLA trial analyses

J. Mayadev[1*], J. C. Vázquez Limón[2], F. J. Ramírez Godinez[3], M. Leiva[4], L. D. C. Cetina-Pérez[5], S. Varga[6], A. Molina Alavez[7], A. E. Alarcon-Rozas[8], N. Valdiviezo[9], C. Acevedo[10], A. Figueroa[11], A. Santini[12], L. Vera[13], F. Rey[14], Z. Kahán[15], P. Galaz[16], G. Meléndez Mier[17], X. Wu[18], M. Mandai[19], R. Shapira-Frommer[20], M. D. P. Estevez-Diz[21], S. Limaye[22], W. Xin[23], H. Dry[24], M. A. S. Broggi[25], D. Y. Yuan[26], R. A. Stewart[27] & B. J. Monk[28]

Risk of progression & death reduced by at least 95% in both treatment arms if no ctDNA detected at cycle 6, day 1



Mayadev et al. Ann Oncol 2025 Sep;36(9):1047-1057.

Journal of Clinical Oncology®
An American Society of Clinical Oncology Journal

Meeting Abstract: 2025 ASCO Annual Meeting I

FREE ACCESS | Care Delivery/Models of Care | May 28, 2025

Automated conversational artificial intelligence (AI) for outpatient malignant bowel obstruction (MBO) symptom monitoring.

Authors: Ainhoa Madariaga, Isabel Tuñon, Sara Sánchez-Castro, Marta Ruiz, Ainhoa Herrero, Carla María Nuñez, María Maiz, ... SHOW ALL ... , and Andrea Modrego | AUTHORS INFO & AFFILIATIONS

J Clin Oncol **43**, 1547(2025) • Volume 43, Number 16_suppl • DOI: 10.1200/JCO.2025.43.16_suppl.1547

Reframing Success

- Successful follow-up is not just "we detected recurrence early”
- It is patients living as well as possible and equipped to manage what comes next
- It is addressing late effects, function, psychological recovery and return to life
- It is ‘’the right person had the right contact at the right time" (risk-stratification & good survivorship care)
- Surveillance is still necessary when recurrence is salvageable – not ‘one size fits all’

Call to Action – next Monday…

- Treat follow-up as a survivorship interaction, not just a recurrence check
- Follow-up should not just be "scan result, bloods, see you in 3 months"
- Include one survivorship element into every patient contact:
  - Late effects
  - A care plan that has been updated
  - One PROM
  - A question about what the patient is struggling with now
  - A referral to a web-based resource or to an allied health professional

Take Home Messages

1. Least examined component of cancer care and has high cost
2. We have been measuring success by the wrong yardstick
3. Areas for improvement: ‘where’ and ‘how’ & what we measure
4. Not one size fits all

THE BOTTOM LINE

Survivorship care fails not for lack of intent but for lack of capacity

THANK YOU!