Do experiences of care at the end of treatment influence the psychosocial wellbeing of Adolescents and Young Adults (AYAs) with cancer?

research
prevention
support

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Why AYA patient experiences?

- Availability of AYA specific information / resources
- Increasing recognition of unique challenges of AYA care
- Transition to follow-up care in the adult system important but under-studied
- Information on care quality needed to help guide & evaluate initiatives
  - Clinical information, but also
  - Patient perspective

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The AYA Experiences of Care project

To describe Australian AYA’s experience of cancer care to identify:

i) aspects of care being done well

ii) aspects of care could be improved

iii) impact on experiences of a health professional support contact

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Patient experience measures

Patients report on whether specific care events or components occurred

Areas assessed can include:

- Communication
- Informational & emotional support
- Access to services
- Continuity of care
- Being treated with respect

Patient experience measures

End of treatment care experiences:

- Treatment summary
- Follow-up care plans
- Follow-up tests required
- How to manage side effects
- Signs/symptoms to look out for

Quality of life

- FACT-G

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Sample recruitment

Eligibility

- Aged 15 and 24 when diagnosed
- Any cancer – except Melanoma <3mm thick or stage I or II
- Between 3 months - 2 years post diagnosis

Recruitment

- Victoria and NSW Cancer Registries (CR)
- CRs: Contact treating clinician to inform of patient approach—clinician can veto approach
- CR-mail survey to patients (those <18, parents/guardian receive survey information, provide consent)

Survey

- Pencil and paper surveyed mailed
- Option to complete online (12% did)

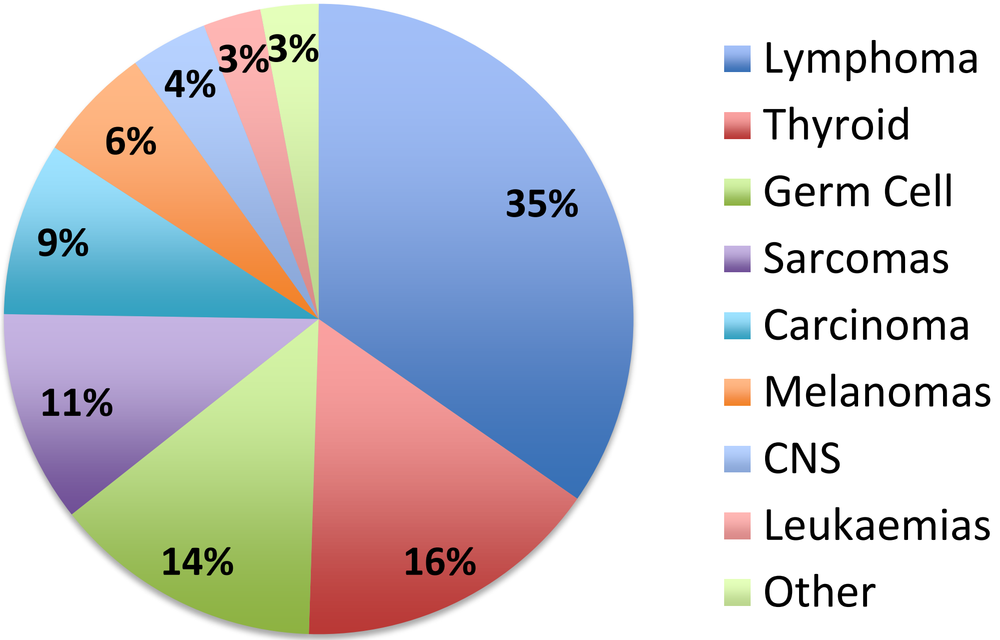
Participants

209 valid surveys returned (29% response rate)

207 final sample

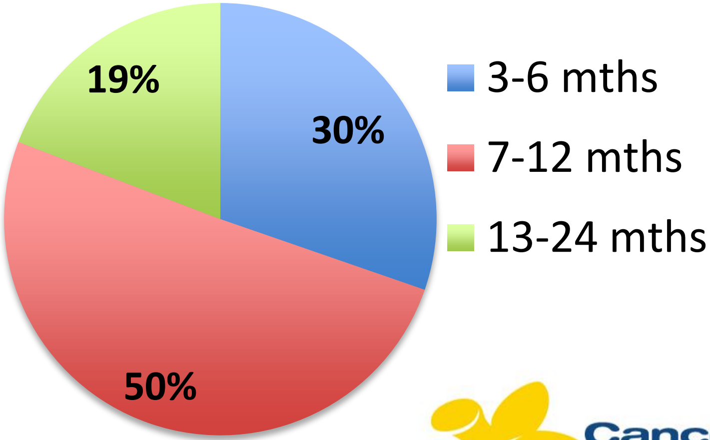
161 had competed treatment (78%)

Participant characteristics



57% Female

67% 20-24 years



9.3 months post-diagnosis

Treatment details

Surgery: 76%

57 centres

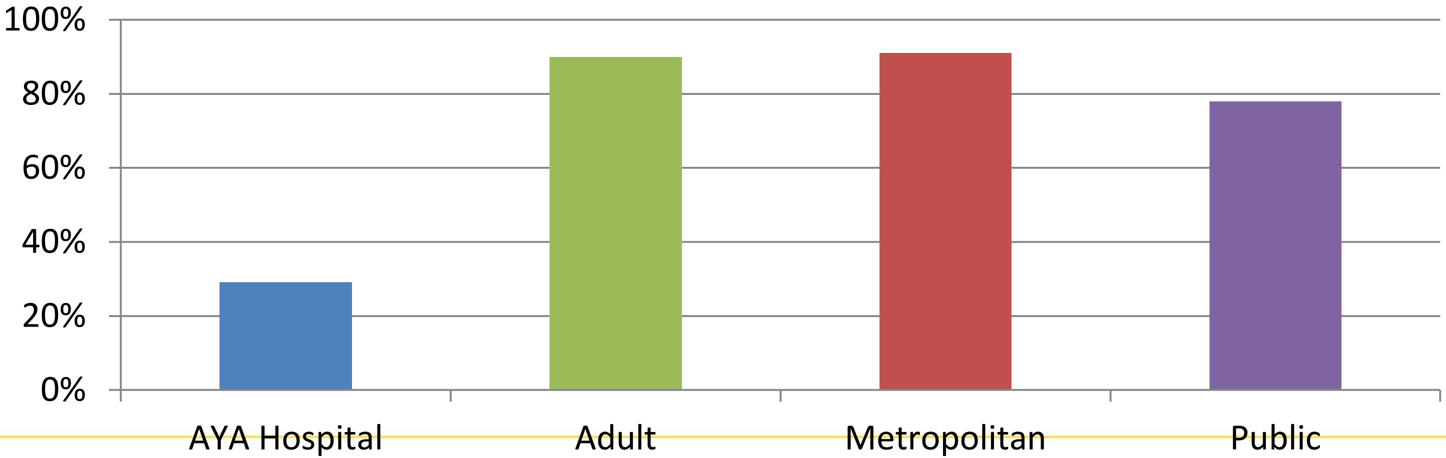
Chemotherapy: 56%

47 centres

Radiotherapy: 30%

23 centres

Proportion of participants attending each type of hospital



‘End of treatment’ care experiences

At the end of cancer treatment were you:	Yes, definitely	Yes, I think so	No / Not sure
Given written follow-up care plan?	27%	24%	50%
Given written summary of your care?	22%	19%	59%
Told about follow-up tests/check-ups	69%	27%	4%
Told about new symptoms to look for?	32%	25%	43%
Offered help returning to daily life?	21%	26%	54%
Told about the emotions young people might face after finishing treatment?	19%	25%	56%
Told how to manage symptoms/side effects? ^	24%	32%	27%

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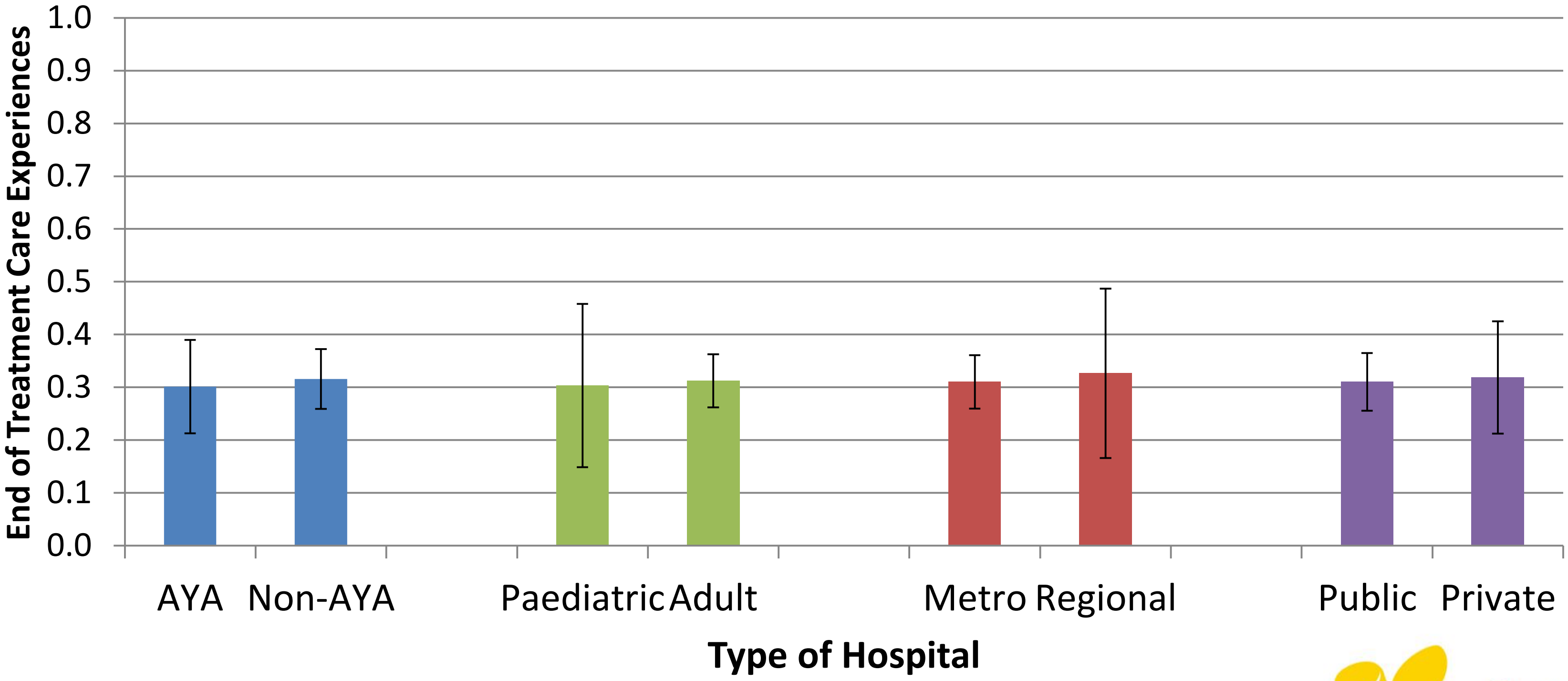
^ This item was not relevant for 17% of patients.

Influence of treatment centre on ‘end of treatment’ care experiences



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Supportive 'end of treatment' care improves wellbeing

	B [95%CI]	***p***
Functional Wellbeing	5.45 [2.37 - 8.52]	**.001**
Emotional Wellbeing	2.40 [.24 - 4.56]	**.030**
Social Wellbeing	5.46 [2.79 - 8.13]	**<.001**
Physical Wellbeing	2.39 [-.23 - 5.00]	.074
Overall Wellbeing	15.70 [7.71 - 23.69]	**<.001**

Analyses are adjusted for demographic and treatment-related factors independently shown to influence quality of life scores (gender, remoteness of residence, cancer diagnosis and time since diagnosis).

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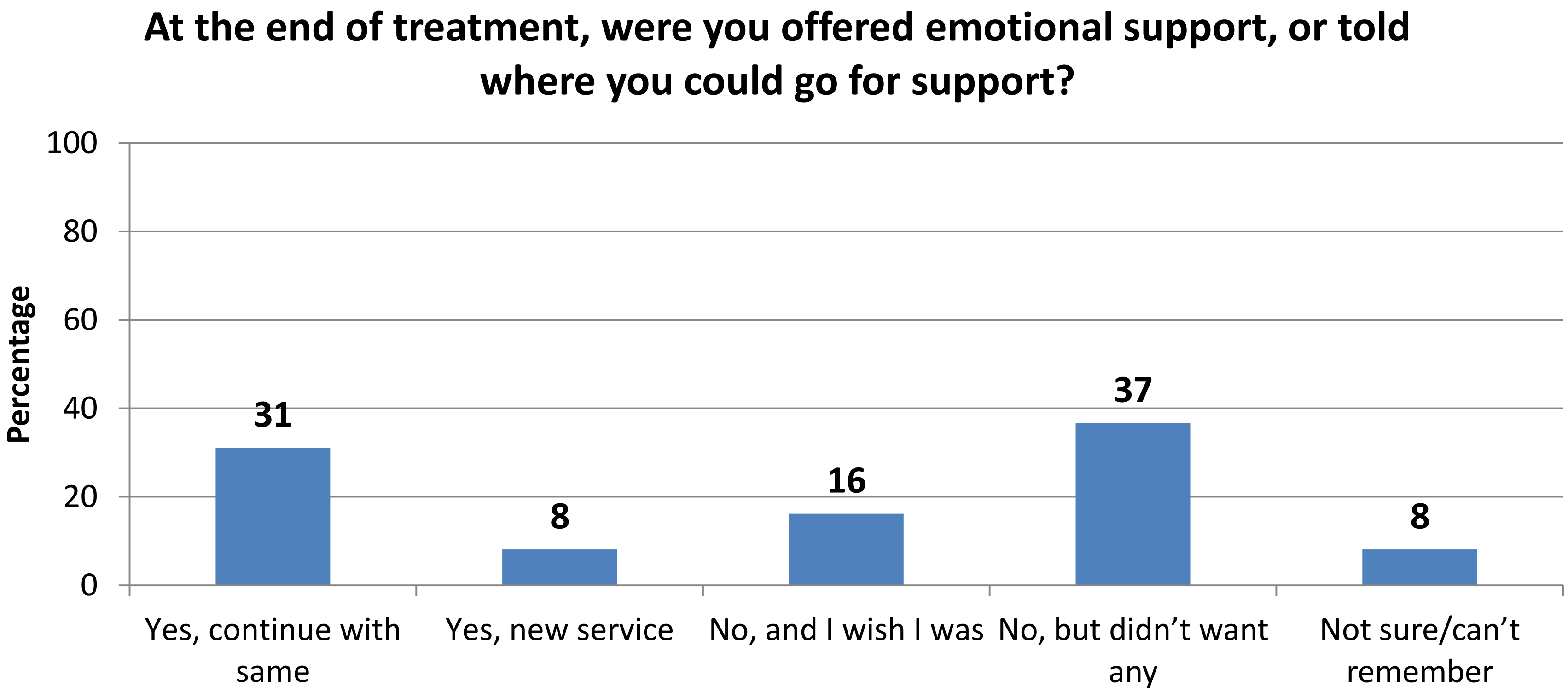
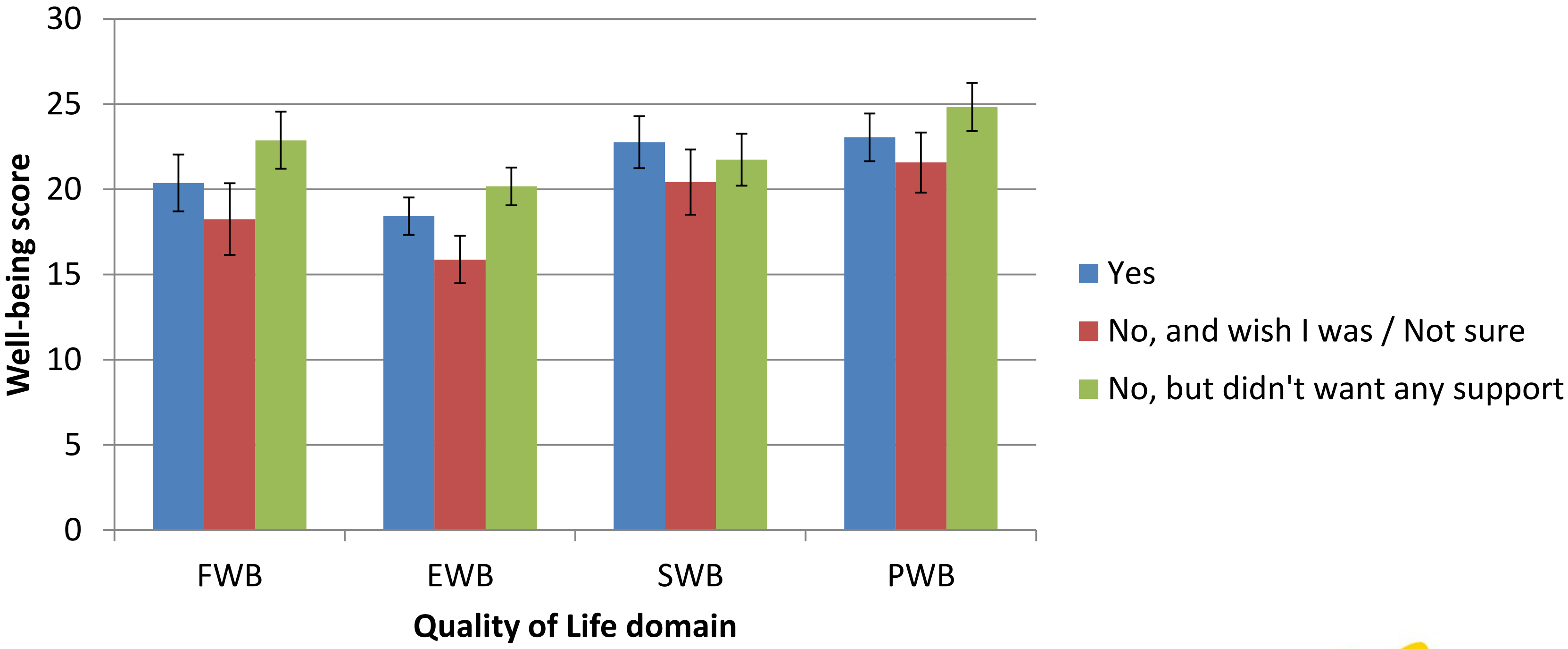
Referral to services



Relationship with well-being



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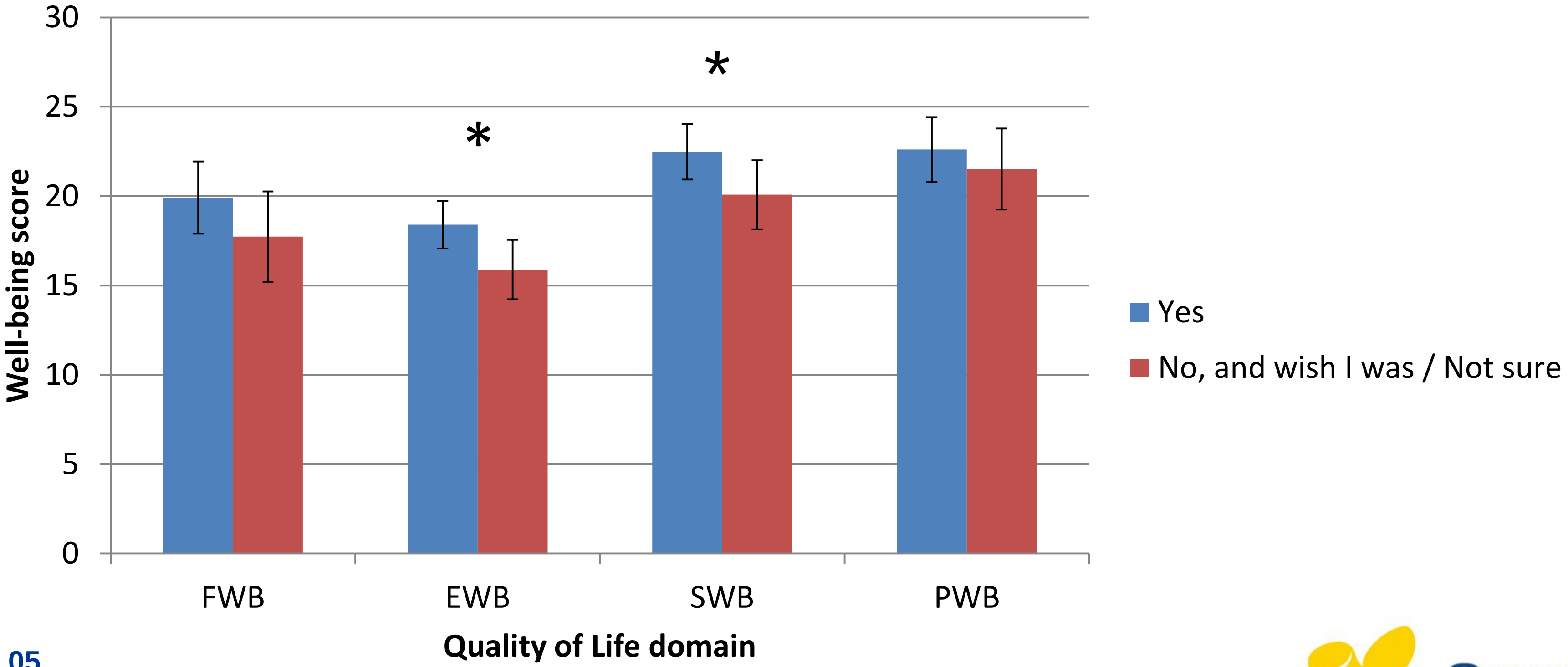

*** *p* < .05.**

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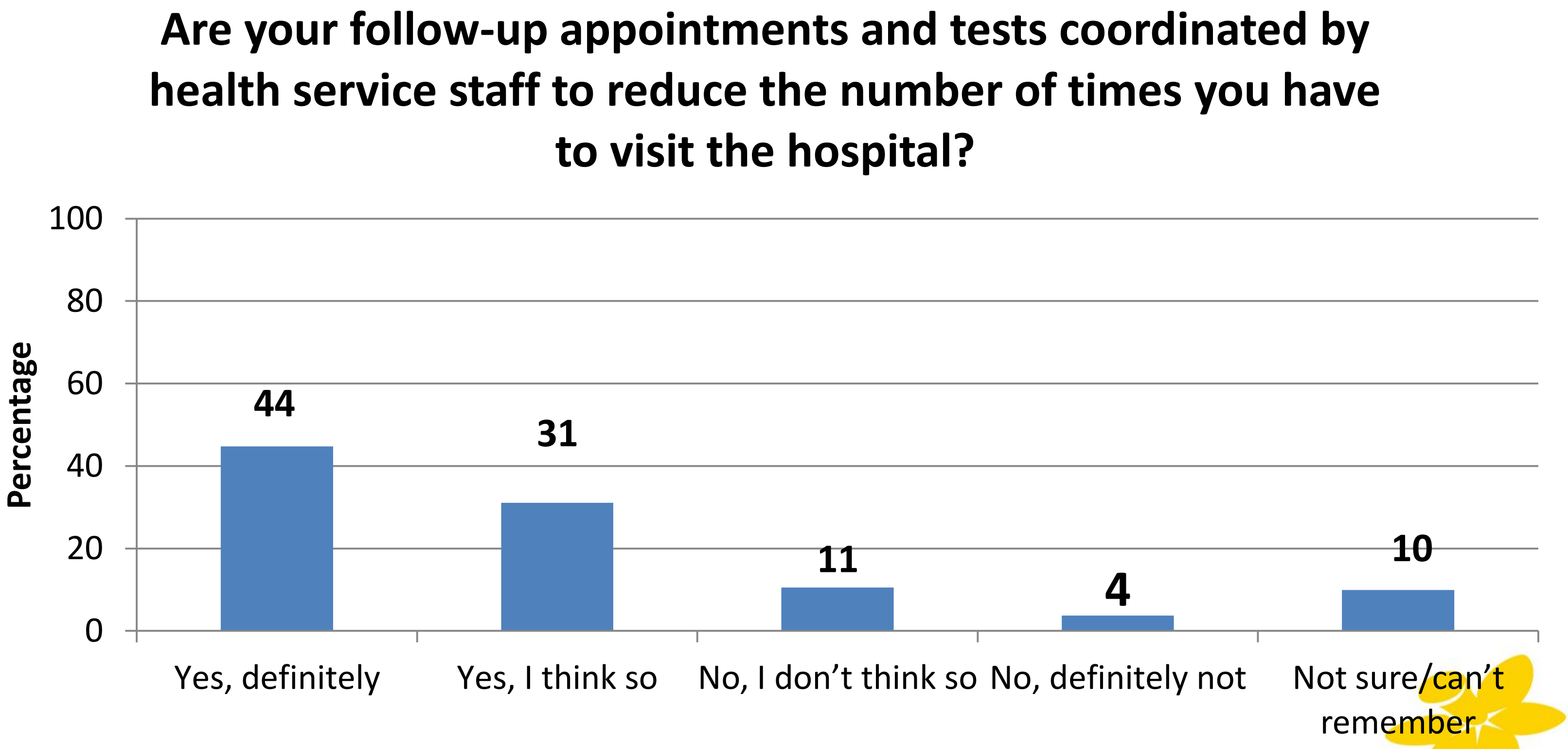
Coordinated follow-up appointments and tests



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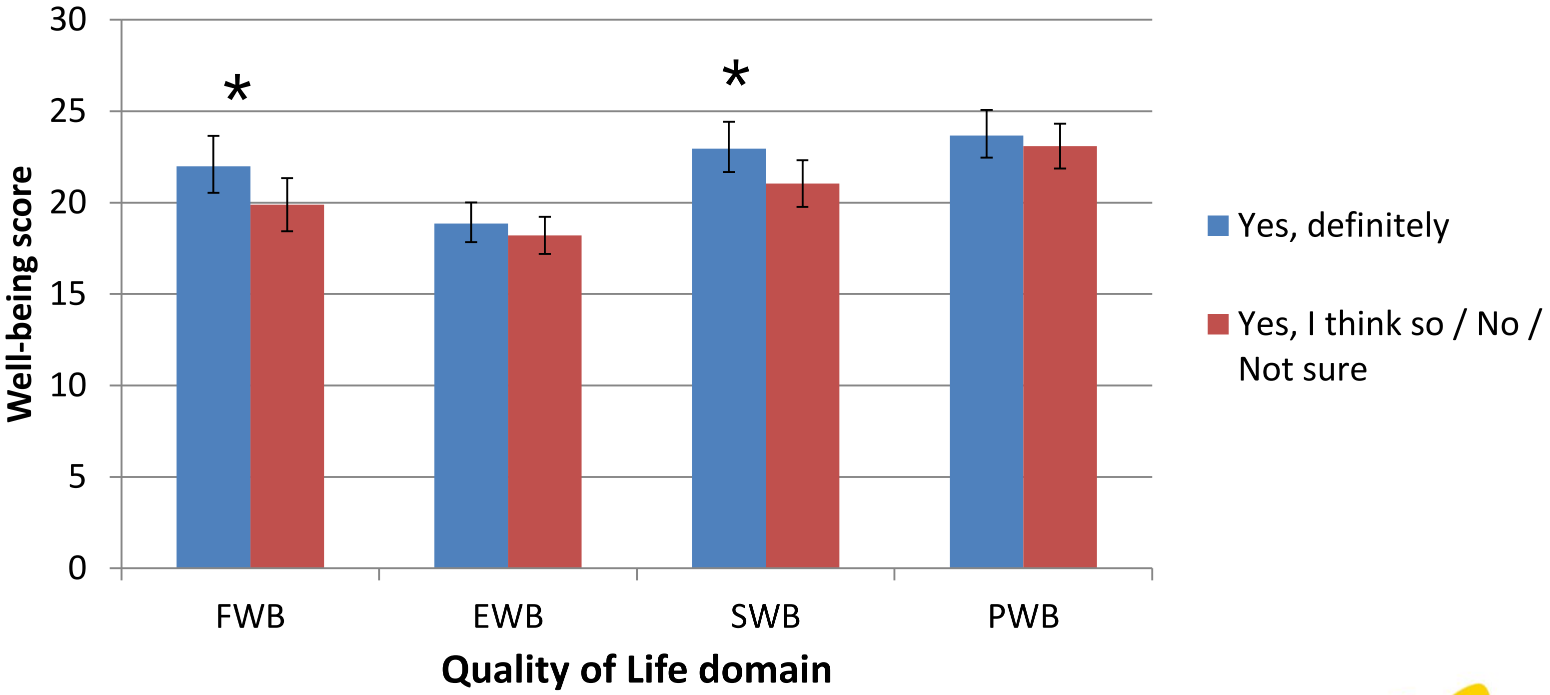
Relationship with well-being



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Limitations

- Low response rate
- Self-reported experiences
- Accuracy of patient reflection?

Implications

- There is a need for end-of-treatment care to be more routinely provided
  - Provision of this care did not differ by diagnosis or treatment centre attended
- Providing such care may improve AYAs' well-being into survivorship

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Research team

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Connecting young people living with cancer with specialist care and support

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Healthier Kids. Healthier Future.

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