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Melanoma follow up: time to generate the evidence

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Abstract. Research is needed into current melanoma follow-up practices and their implications for patients and society. We highlight the need and suggest a way forward.

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Australia has the world's highest incidence of cutaneous melanoma.[1] Melanoma is Australia's fourth most commonly diagnosed cancer,[2] with 10 342 new cases in 2007 (representing 10% of all cancers) and 1279 deaths from the disease.[1] The incidence rate for melanoma is increasing, as is the survivor population, mainly due to improvements in diagnosis and primary treatment.[3] In 1988–2004, melanoma patients had a 5-year survival rate of 92%.[4] The growing population of survivors increases the significance of decisions regarding follow-up care and its impact on the health budget and workforce, particularly as melanoma is the most common cancer diagnosed in Australians aged 15–29 years, who may need life-long follow up.[5]

Regular follow up after the successful treatment of invasive melanoma represents standard care. The conventional aim of melanoma follow up is to improve survival through the early detection of recurrence and through the prevention (via SunSmart education) and early detection of any new primary melanoma and non-melanoma skin cancer. The risk of developing a second primary melanoma is 8–12%.[6–8] The risk of melanoma recurrence is dependent on the cancer staging, with 10-year recurrence rates ranging from ~10% for stage IA to ~65% for stage IIC.[9] Recurrence has been known to occur up to 16 and even 27 years after primary treatment.[10,11] This underscores the need for longer-term follow up, as well as for educating patients about possible recurrence.

What challenges face melanoma follow up in Australia?

Australian and New Zealand guidelines are based on low-level evidence, mainly expert opinion (Level IV evidence).[2] Given the low level of evidence available, it is unsurprising that guidelines in other countries, such as the USA and UK,[12,13] vary considerably on key issues, including:

- which practitioners should provide follow up;
- the frequency of follow-up visits;
- what the content of follow up should be, namely whether it should include SunSmart education and any of a wide range of different diagnostic tests; and
- the stratification of follow-up recommendations by prognostic variables (e.g. sentinel lymph node status).

It is reasonable to hypothesise that lower-level evidence results in increased variation in clinical practice, as clinicians give less weight to guidelines and more to individual judgement and experience. There is evidence of variation in melanoma follow-up practices overseas.[14] A recently published systematic review found significant worldwide variation in melanoma follow up with respect to the frequency of scheduled visits, the type and frequency of imaging and laboratory assessment used, and the speciality of treating doctors.[15] No published research has examined such variation in Australia.

Pilot data from a 2012 survey of 117 Australian melanoma follow-up patients points to wide variation in practice.[16] This data indicates that melanoma follow up is provided by a range of practitioners, including dermatologists, surgeons and general practitioners, with patients sometimes reviewed by more than one provider. Within this framework, there is opportunity for the duplication of effort and testing and for inconsistent care. With regard to visit frequency, Turner *et al*. argue that current Australian and New Zealand guidelines 'probably provide rather small gains (in terms of earlier diagnosis of recurrence or new primary) at the expense of a large number of additional clinic

visits.'[9] Moreover, anecdotal evidence suggests that a variety of diagnostic tests, including computed tomography and positron emission tomography scanning, are frequently used in melanoma follow up in Australia when there is no evidence that they provide benefit. Besides ultrasound 'performed by experienced ultrasonographers . . . [n]o other tests have significant value in patients with localised disease.'[2] Given the expense of these tests, this has significant resource implications. Finally, guidelines lack the evidence needed to tailor recommendations to particular patient groups based on prognostic criteria. For example, 'thin' (<0.1 mm) melanoma is considered 'cured' by primary excision. This compares with melanoma with adverse prognostic features (such as ulceration and lymphovascular invasion), sentinel-node-positive melanoma and 'thick' (>4 mm) melanoma, all of which require a more comprehensive follow-up regime, but exactly how recommendations should be tailored is unknown.

In short, despite their potential impact on patient outcomes and health resources, melanoma follow-up practices in Australia remain poorly documented and understood. As the survivor population increases, so too does the need to identify existing melanoma follow-up practices, to examine their costs and effects, and to agree on possible enhancements.

But how should this be done?

First, we need to identify existing follow-up practices and classify them into a limited number of alternative models of care. This enables the comparison of variables such as provider, visit frequency and diagnostic testing. It is also helpful to define follow up, so as to begin with a list of health outcomes that are of interest when comparing models of care. We propose the following definition of cancer follow up:

Follow up is the scheduled pattern of activity initiated by a health practitioner to follow primary cancer treatment for a specified or indefinite period of time for the purpose of:

- monitoring treatment outcome, detecting early any recurrence or new primary cancer, detecting and managing treatment-related side effects, preventing new primary cancer (via patient education about risk-reducing behaviour); and
- detecting and addressing psychological or other problems.

Activities may include:

- taking patient histories, clinical examination, diagnostic testing, educating patients about self-examination;
- counselling regarding return-to-work and relationship issues, patient involvement in organised support groups, and physical rehabilitation.

It is important to broaden the conventional aim of follow up to include the assessment of psychological problems, as addressing these stands to improve patient wellbeing and adherence to follow-up schedules.[17] There is evidence that ~30% of melanoma patients report clinically relevant psychological distress.[18] Although there is some evidence that early detection of recurrence can improve patient survival[15,19,20] and the benefit of detecting early a new primary melanoma is generally accepted,[21] evidence is inconclusive whether intensive surveillance can meaningfully contribute to early detection;[2] 75% of patients detect their own recurrence outside of scheduled follow-up visits.[2,9]

Evidence first needs to be generated on current follow-up practices to identify models of care (e.g. different providers). Mixed methods can then be used to undertake comparison. The use of mixed methods in evaluating cancer-care programs has already been established.[22] An observational study could begin by linking routinely collected data obtained from different sources, such as practice notes, Medicare, the Pharmaceutical Benefits Scheme and hospital databases.[23] This would enable the comparison of existing models of care with respect to financial costs and key health outcomes, e.g. time to detection of recurrence, time to detection of second primary tumours and overall survival. Observational studies in cancer are essential to generate evidence over the long follow-up period and to identify best practice within a reasonable timeframe.[24] Interviews with melanoma patients and practitioners could be conducted to identify factors that are important in melanoma follow up beyond those evaluated as part of an observational study and for which metrics may not be available, e.g. the degree to which follow-up care is accessible independent of patient income and postcode, and the degree to which care is coordinated across the primary treatment and follow-up stages, such that patients avoid disorientation and gaps in care. Finally, deliberative processes could be used to generate stakeholder consensus on an enhanced model of care.[25] Deliberation could draw on the evidence generated earlier and seek to identify the relative importance of key health outcomes and stakeholder preferences.

In summary, no published study has reviewed current melanoma follow-up practices in Australia and their implications for patients and society. We need to identify existing practices in melanoma follow up and establish how they vary. We can then use mixed-methods research to compare costs and effects and to examine patient and practitioner preferences for care, along with any emerging ethical issues. It may be that less-intensive follow up is preferable to some patients and more cost effective with respect to health outcomes. For instance, psychological problems may be increased as much as diminished by intensive follow up, in so far as many patients experience increased anxiety before and during follow-up visits: 'a balance is required between inducing additional patient anxiety and providing much wanted reassurance.'[26] Moreover, practitioners may prefer to adopt a shared-care approach, in which specialists and general practitioners alternate or otherwise coordinate care, with different combinations possible.[27] Patients may also prefer this kind of shared care if travel[26] or waiting times are significant for them. The suggested research could generate the evidence needed to ensure safe, effective and economically sustainable melanoma follow up that is acceptable to patients and providers.

Competing interests

The authors declare that there are no competing interests.

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References

1 Australian Institute of Health and Welfare, Australasian Association of Cancer Registries. Cancer in Australia: an overview. Canberra: AIHW; 2010.

2 Australian Cancer Network Melanoma Guidelines Revision Working Party. Clinical practice guidelines for the management of melanoma in Australia and New Zealand, Cancer Council Australia and Australian Cancer Network. Wellington: Sydney and New Zealand Guidelines Group; 2008.

3 Gamble RG, Jensen D, Suarez AL, Hanson AH, McLaughlin L, Duke J, *et al*. Outpatient follow-up and secondary prevention for melanoma patients. *Cancers* 2010; 2(2): 1178–97. doi:10.3390/cancers2021178

4 Australian Institute of Health and Welfare, Cancer Australia, Australasian Association of Cancer Registries. Cancer survival and prevalence in Australia: cancers diagnosed from 1982 to 2004. Canberra: AIHW; 2008.

5 Australian Institute of Health and Welfare (AIHW). Cancer in adolescents and young adults in Australia. Canberra: AIHW; 2011.

6 Titus-Ernstoff L, Perry AE, Spencer SK, Gibson J, Ding J, Cole B, *et al*. Multiple primary melanoma: two-year results from a population-based study. *Arch Dermatol* 2006; 142(4): 433–8. doi:10.1001/archderm.142.4.433

7 Bradford PT, Freedman DM, Goldstein AM, Tucker MA. Increased risk of second primary cancers after a diagnosis of melanoma. *Arch Dermatol* 2010; 146(3): 265–72. doi:10.1001/archdermatol.2010.2

8 Yang GB, Barnholtz-Sloan JS, Chen Y, Bordeaux JS. Risk and survival of cutaneous melanoma diagnosed subsequent to a previous cancer. *Arch Dermatol* 2011; 147(12): 1395–402. doi:10.1001/archdermatol.2011.1133

9 Turner RM, Bell KJ, Morton RL, Hayen A, Francken AB, Howard K, *et al*. Optimizing the frequency of follow-up visits for patients treated for localized primary cutaneous melanoma. *J Clin Oncol* 2011; 29(35): 4641–6. doi:10.1200/JCO.2010.34.2956

10 Otsu U, Fukui N, Iki M, Moriwaki S, Kiyokane K. Case of cutaneous malignant melanoma surviving 16 years with late recurrence. *J Dermatol* 2009; 36(11): 598–603. doi:10.1111/j.1346-8138.2009.00719.x

11 Tomas S. Recurring melanoma – a case study. *Aust Fam Physician* 2007; 36: 1015–6, 1024.

12 Bichakjian CK, Halpern AC, Johnson TM, Foote Hood A, Grichnik JM, Swetter SM, *et al*. Guidelines of care for the management of primary cutaneous melanoma. American Academy of Dermatology. *J Am Acad Dermatol* 2011; 65(5): 1032–47. doi:10.1016/j.jaad.2011.04.031

13 Marsden JR, Newton-Bishop JA, Burrows L, Cook M, Corrie PG, Cox NH, *et al*. Revised UK guidelines for the management of cutaneous melanoma 2010. *J Plast Reconstr Aesthet Surg* 2010; 63(9): 1401–19. doi:10.1016/j.bjps.2010.07.006

14 Virgo KS, Chan D, Handler BS, Johnson DY, Goshima K, Johnson FE. Current practice of patient follow-up after potentially curative resection of cutaneous melanoma. *Plast Reconstr Surg* 2000; 106(3): 590–7.

15 Cromwell KD, Ross MI, Xing Y, Gershenwald JE, Royal RE, Lucci A, *et al*. Variability in melanoma post-treatment surveillance practices by country and physician specialty: a systematic review. *Melanoma Res* 2012; 22(5): 376–85. doi:10.1097/CMR.0b013e328357d796

16 Mitchell J, Street J, Bessen T, Neuhaus S. The patient experience of melanoma follow-up: an on-line survey. In Flinders Centre for Innovation in Cancer (FCIC) Survivorship Conference; 1–3 February 2013. Adelaide. Available at http://fcic-2013.p.asnevents.com.au/event/abstract/4370 [Verified 16 August 2013]

17 Rychetnik L, McCaffery K, Morton R, Irwig L. Psychosocial aspects of post-treatment follow-up for stage I/II melanoma: a systematic review of the literature. *Psychooncology* 2013; 22(4): 721–36.

18 Kasparian NA, McLoone JK, Butow PN. Psychological responses and coping strategies among patients with malignant melanoma: a systematic review of the literature. *Arch Dermatol* 2009; 145(12): 1415–27. doi:10.1001/archdermatol.2009.308

19 Garbe C, Paul A, Kohler-Spa H, Ellwanger U, Stroebel W, Schwarz M, *et al*. Prospective evaluation of a follow-up schedule in cutaneous melanoma patients: recommendations for an effective follow-up strategy. *J Clin Oncol* 2003; 21(3): 520–9. doi:10.1200/JCO.2003.01.091

20 Garbe C. A rational approach to the follow-up of melanoma patients. *Recent Results Cancer Res* 2002; 160: 205–15. doi:10.1007/978-3-642-59410-6_24

21 Balch CM, Gershenwald JE, Soong SJ, Thompson JF, Atkins MB, Byrd DR, *et al*. Final version of 2009 AJCC melanoma staging and classification. *J Clin Oncol* 2009; 27(36): 6199–206. doi:10.1200/JCO.2009.23.4799

22 Brazier A, Cooke K, Moravan V. Using mixed methods for evaluating an integrative approach to cancer care: a case study. *Integr Cancer Ther* 2008; 7(1): 5–17. doi:10.1177/1534735407313395

23 Haji Ali Afzali H, Gray J, Beilby J, Holton C, Banham D, Karnon J. A risk-adjusted economic evaluation of alternative models of involvement of practice nurses in management of type 2 diabetes. *Diabet Med* 2013; 30(7): 855–63. doi:10.1111/dme.12195

24 Wolin KY, Colditz GA. Design and conduct of intervention-based research among cancer survivors. *Cancer Epidemiol Biomarkers Prev* 2011; 20(10): 2078–84. doi:10.1158/1055-9965.EPI-11-0605

25 Smith G, Wales C. Citizen juries and deliberative democracy. *Polit Stud* 2000; 48: 51–65. doi:10.1111/1467-9248.00250

26 Morton RL, Rychetnik L, McCaffery K, Thompson JF, Irwig L. Patients' perspectives of long-term follow-up for localised cutaneous melanoma. *Eur J Surg Oncol* 2013; 39(3): 297–303. doi:10.1016/j.ejso.2012.12.017

27 Rychetnik L, Morton RL, McCaffery K, Thompson JF, Menzies SW, Irwig L. Shared care in the follow-up of early-stage melanoma: a qualitative study of Australian melanoma clinicians' perspectives and models of care. *BMC Health Serv Res* 2012; 12: 468. doi:10.1186/1472-6963-12-468