

Development and Alpha-testing of a Patient Decision Aid for Low-risk Thyroid Cancer

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Acknowledgment : This project was funded by the Cancer Institute NSW through the NSW Regional Cancer Research Network

Introduction

The incidence of well-differentiated thyroid cancer (WDTC) has increased due to incidental detection, leading to overdiagnosis and overtreatment. Despite guidelines recommending less aggressive treatment, total thyroidectomy remains common for low-risk cases suitable for hemithyroidectomy or active surveillance.¹ Shared decision-making goes beyond informed consent and involves tailored information and individualised value-based care.² This study describes the development of a decision aid (DA) for low-risk WDTC primarily applicable to Australians but generalisable internationally.

Methodology

International patient decision aid standards were followed to develop and refine the DA.³ A prototype double-sided A4 paper and detailed web-based DA were developed by a multidisciplinary working group (clinicians, behavioural scientists, nurses and consumers) following mixed-methods feedback from clinicians. Patients with low-risk WDTC provided feedback via surveys; iterative changes were made after each of three rounds of responses. Focus groups provided further refinement to the DA. A final clinician survey provided additional feedback and explored implementation implications

Paper-based DA (A4 double sided)

Helping you decide about treatment if you might have a low-risk thyroid cancer



What treatment options may be available? (there is more detail over the page)

Total thyroidectomy	Hemithyroidectomy	Active surveillance
<ul style="list-style-type: none"> The whole thyroid gland (including the cancer) is removed Thyroid hormone tablets must be taken lifelong There is a small chance of needing calcium tablets after surgery 	<ul style="list-style-type: none"> The half of the thyroid gland containing the cancer is removed Some people need to take thyroid hormone tablets after the surgery Calcium tablets are not needed The other half of the thyroid sometimes needs to be removed in the future 	<ul style="list-style-type: none"> This is an option if the cancer is less than 10mm in size The cancer is not removed but is monitored with scans Surgery can be chosen later if your preferences change Surgery is recommended if the cancer grows This is not available at all centres and is only suitable for some people

About "low-risk" thyroid cancers

- Low-risk thyroid cancers are small and have not grown outside the thyroid
- The chance of low-risk thyroid cancer coming back or spreading is less than 10%
- The chance of dying from low-risk thyroid cancer is close to zero

Deciding about treatment for low-risk thyroid cancer

- There are different treatment options that may be suitable
- The information here is to help you understand your choices
- This information could be used in discussion with your healthcare team and trusted friends or family
- Your surgeon or endocrinologist will work with you to provide clear advice on the best options for your treatment

These are some questions I have...

How do I feel about having surgery?

I would prefer to have my whole thyroid removed, and minimise the chances of another operation in the future	or	I would prefer to have a smaller operation first, minimising side effects but knowing there is a chance that I might need a second operation in the future	or	I would prefer to avoid surgery if possible
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How do I feel about the cancer coming back or growing?

I would prefer the cancer to be removed and I would do anything to decrease my chances of cancer returning	or	I would prefer the cancer to be removed now	or	I am happy that the remaining thyroid gland will need monitoring	or	I am happy to accept that the cancer is still present, and will be monitored closely
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How do I feel about taking tablets regularly?

I do not mind taking tablets for thyroid hormone or calcium every day	or	I would like to avoid taking tablets every day if possible
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What are the main pros and cons for each treatment option?



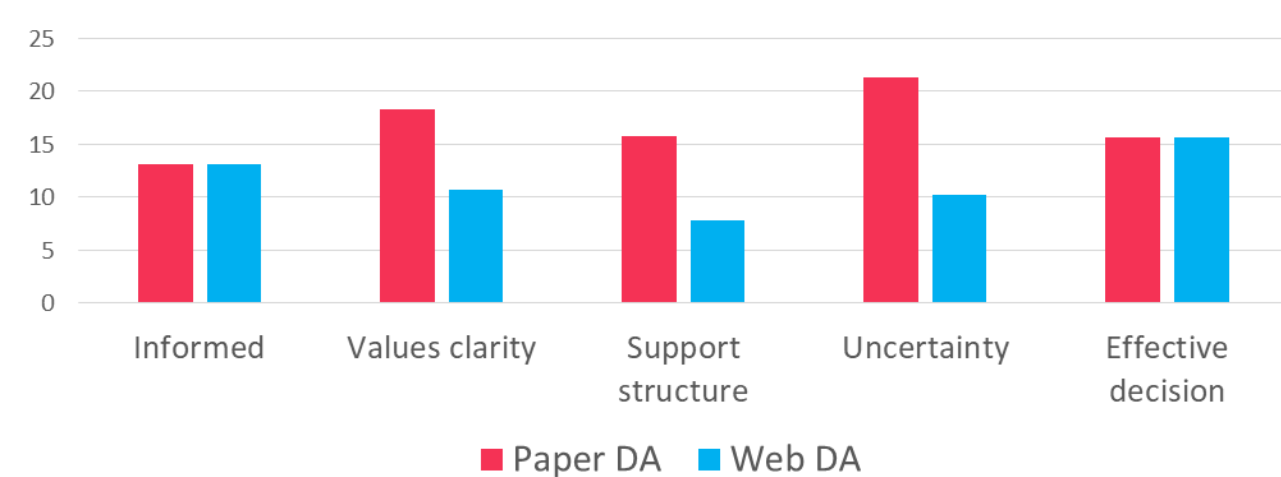
	Total thyroidectomy	Hemithyroidectomy	Active surveillance
What is involved now?	You have surgery to remove <i>all of</i> your thyroid gland	You have surgery to remove the <i>half</i> of your thyroid gland with cancer	You do not undergo any surgery unless the cancer grows over time
What is involved over the next 5 years?	After surgery you may have check-ups to ensure the cancer has not recurred		You will have check-ups every 6-12 months with ultrasound
What are the benefits?	You remove the cancer right away		Avoid surgery for a cancer that might never cause you harm
What is my chance of dying of thyroid cancer in the next 10 years?	Less than 1%		
What is the chance of cancer growing or spreading in the next 5 years?	Less than 5% Recurrence can be detected with ultrasound or blood tests	5-10% Recurrence or growth can be detected with ultrasound	
How long will I need to take off work initially?	Most people return to work within 1-2 weeks of their operation		None (you do not have surgery)
Will I need thyroid hormone tablets for the rest of my life?	Yes, in all cases	30-50% chance of requiring	No
What is the chance of needing calcium and vitamin D tablets for the rest of my life?	2-5% chance	Close to zero	Zero
What is the chance of major change in my voice volume or quality?	2-4% chance	1-2% chance	Close to zero
Will I need radioactive iodine?	Radioactive iodine is not recommended for 'low-risk' cancers. It can only be given if the whole thyroid has been removed		

If you would like more detailed information, please scan the QR code to visit this website https://thyroidology.au/thyroid_aid

Results

Initial feedback from 42 surgeons and 82 endocrinologists indicated that >98% were open to using a standardised DA in consultations, with 57% requesting a hybrid paper and web-based DA. The multidisciplinary group reviewed 28 patient survey responses for the paper DA and 18 for the website (89% female, 86% >50 years, 79% metropolitan, 74% completed high school). Changes made over three iterative cycles focused on presentation of information and refinement of terminology. Decisional conflict was low (Fig1) and acceptability high (Table 2). A final survey of 20 clinicians suggested that most preferred the paper DA to be introduced within a consultation and the web-DA used more selectively post consultation. Perceived implementation barriers include time and increased complexity of communication.

Ottawa Decisional Conflict Survey* (Fig 1)



*Scores range from 0 (no decisional conflict) to 100 (extremely high decisional conflict). The figure shows a comparison of decisional conflict between the Paper DA and Web DA across different subscales of the survey.

Ottawa Acceptability Survey (Table 2)

Criteria	Paper DA	Web DA
Information Rating (Excellent/Good)	96% (50%/46%)	100% (50%/50%)
Length of DA (Just Right)	100%	83%
Amount of information (Just Right)	92%	83%
Usefulness	96%	100%
Perceived Bias	12%	18%

Conclusion

Patients and clinicians value informative resources to assist shared decision-making. This hybrid paper and web-based DA is ready for testing within clinical practice with a focus on implementation.

References

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