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thyroid cancer trust

Radioactive iodine treatment in thyroid cancer: a UK-wide patient survey

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Radioiodine I131 in Thyroid Cancer

- Radioiodine (RAI) improves disease free survival in differentiated thyroid cancer¹
- RAI complications significantly impact on QoL²
- Thyroid cancer QoL scores are lower than for other cancer types³:





Quality of Life and Radioiodine

- RAI treatment decisions impact on QoL:
 - Recombinant TSH vs. thyroid hormone withdrawal⁴
 - Duration of low-iodine diet⁵
 - Radioiodine dose⁶
- Inadequate/inaccurate information about RAI frequently worsens patient experience⁷
- Thyroid cancer patients have unmet informational, psychological and emotional support needs⁸



Aims

- This survey aims to establish patient experience of radioiodine treatment throughout the UK, to identify where practice differs and where informational support could be improved.



Methodology

Treatment Journey

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- First UK-wide survey of thyroid cancer patients undergoing radioiodine therapy
- Conducted in 65 UK hospitals in 2016:
 - Questionnaires provided in clinics
 - Online questionnaires



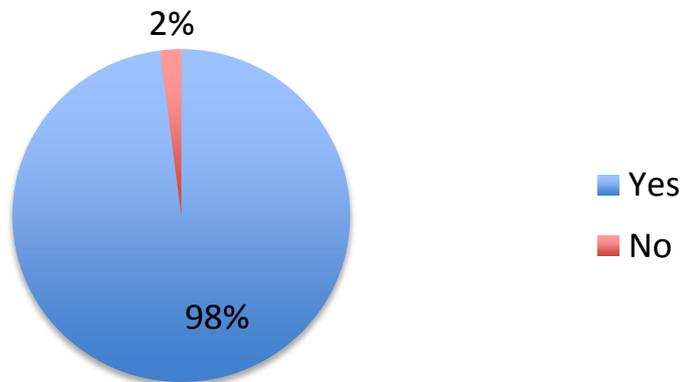
Results: Overview

- Participants recruited from 65 UK hospitals
- Total = 396 respondents
- Gender = 81% female
- Median age = 50-59

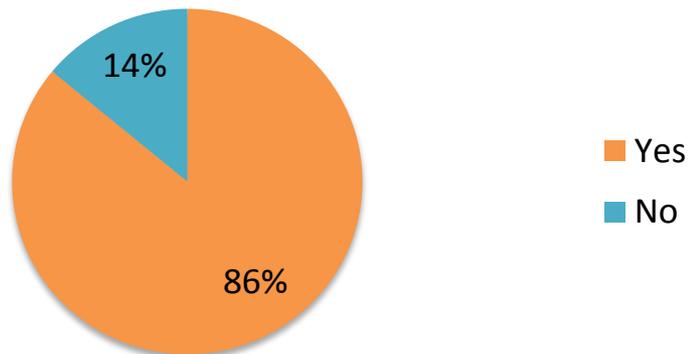


Results: Overview

RAI Information Provision



RAI Information Satisfaction



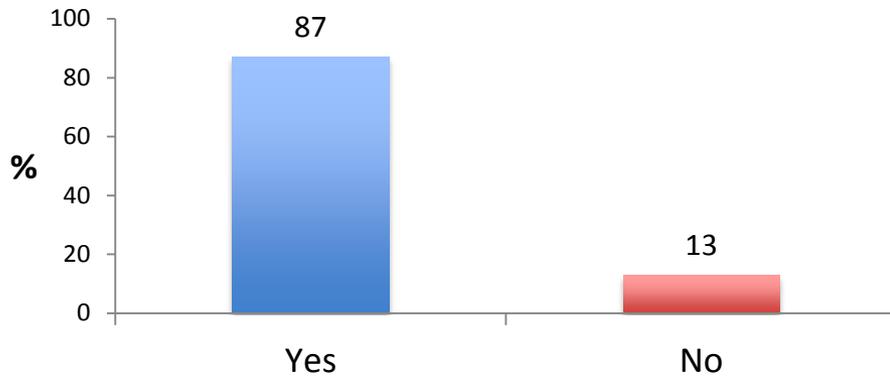
Reasons for dissatisfaction with RAI information provision:

- Low iodine diet
- Radiation exposure:
 - Disposal of clothes
 - Use of mobile phones
 - Children/maternity/breast feeding
- Side effects
- Emotional aspects

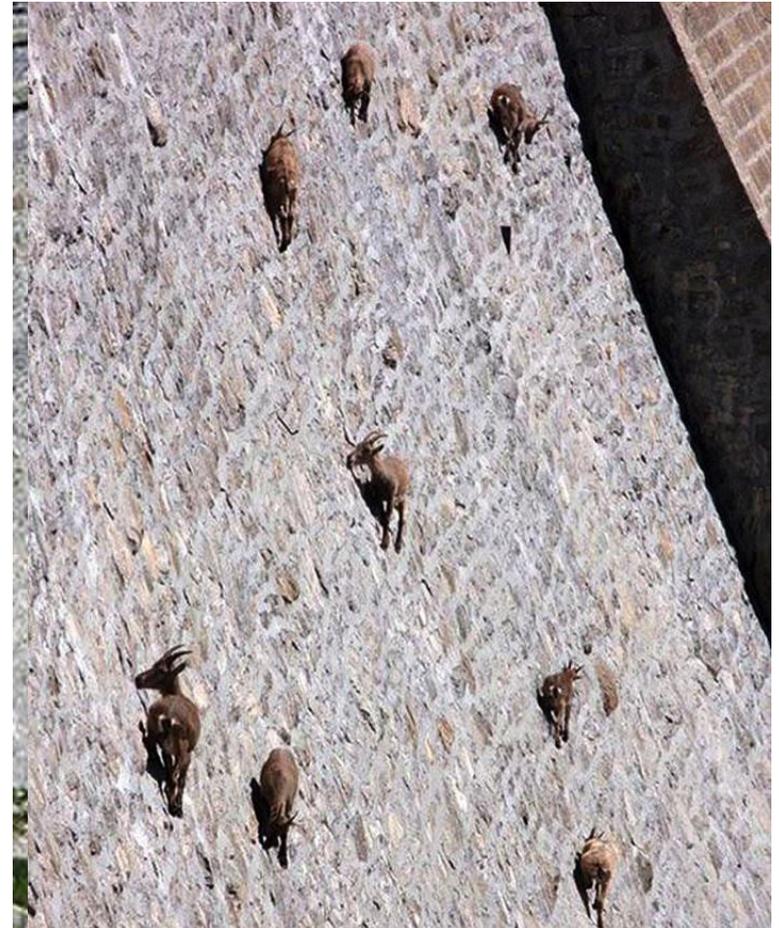
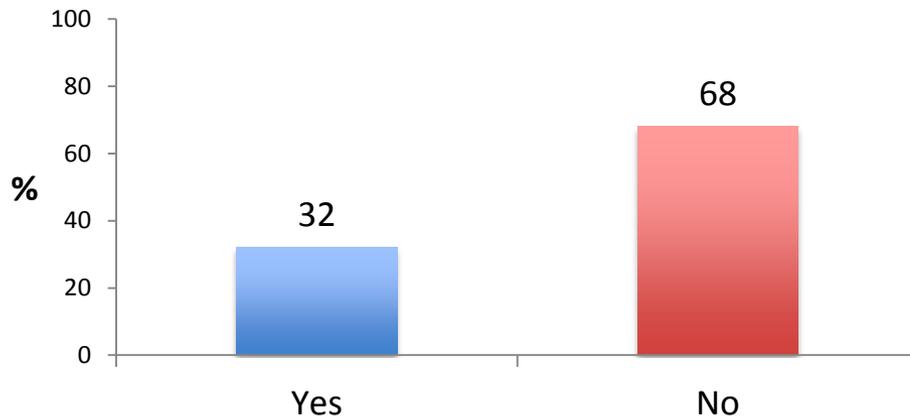


Low Iodine Diet

Low Iodine Diet Advised



Low Iodine Diet Continued in Hospital





Treatment Delivery

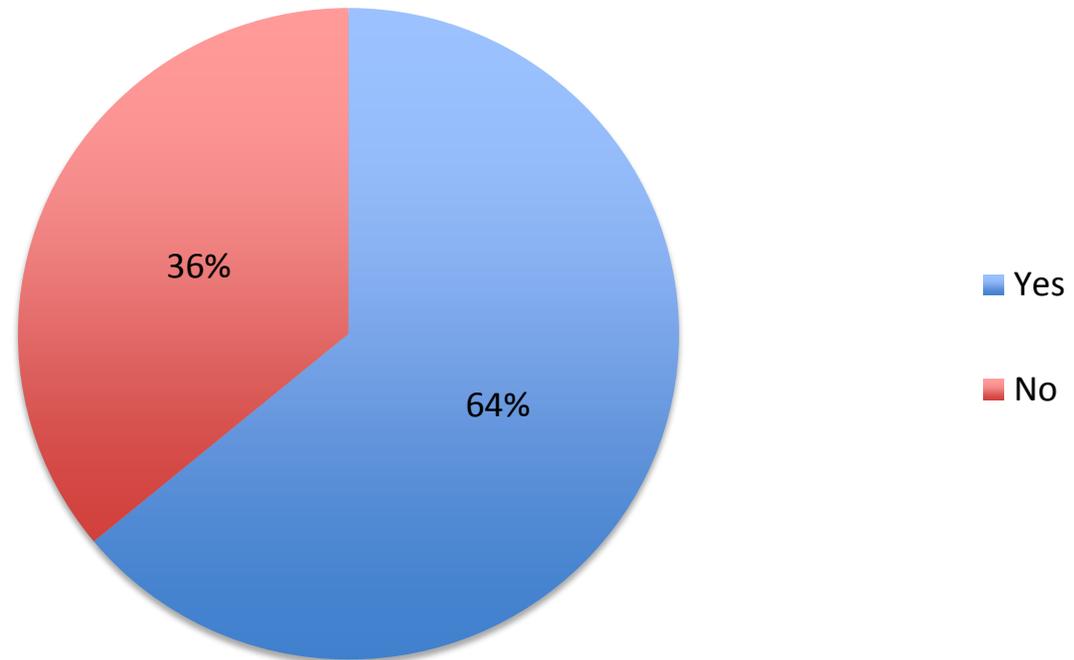
- Mean hospital stay = 2.7 days
- Range:
 - Outpatient treatment (16 patients)
 - 10 days (1 patient)
- Length of stay coinciding with expectations = 80%





Recombinant TSH vs. Thyroxine Withdrawal

Recombinant TSH Utilised





Radiation Exposure

Nursing Contact:

- Percentage receiving adequate nursing contact = 50%

Clothing disposal:

- Percentage advised to dispose clothes = 40%



Relative Contact:

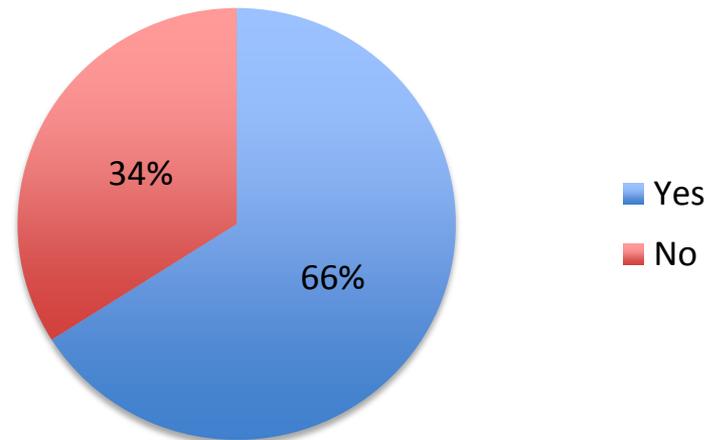
- Avoidance of contact recommendations varied from 1 day to 8 weeks.
- *“Advised not to have visitors”*
- *“Relatives had to wear plastic capes and shoes”*

Mobile phones:

- *“Advised to cover phone in clingfilm”*
- *“Bought a pay-as-you-go phone and disposed it at the end of treatment”*



RAI Side Effects

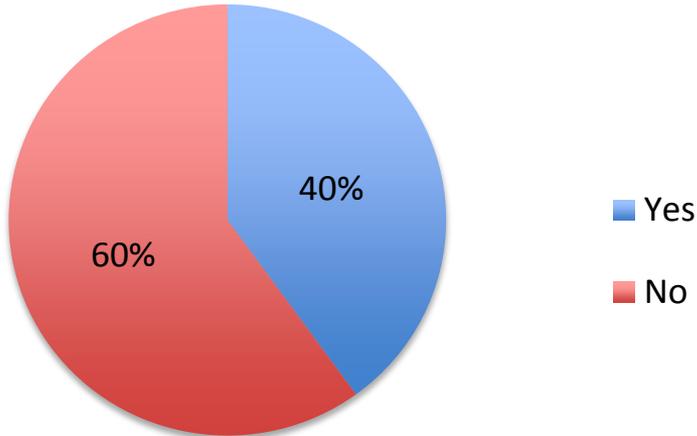


Side Effect	Percentage of Patients (%)
Dry mouth/salivary gland problems	60.4
Taste disturbance	53.7
Sore neck	42.5
Nausea	41.7
Other	34.4



Patient Anxiety

Patients Reporting Anxiety



- *“That it would damage healthy parts of my body as well as attack the cancer cells.”*
- *“Fear of it affecting my hair, fertility and if the procedure would actually work or not.”*
- *“You are ingesting radioactive material, it's very scary and you worry about side effects and exposure to others”*
- *“Being in isolation, away from my family “*
- *“Told I could breast feed until admission for RAI, treatment had to be delayed.”*



Patient Anxiety

“From the time I arrived at the ward, I was treated exceptionally well and kept informed throughout of the process, this allayed any concerns or anxieties I had. Overall, all of the staff that I encountered were excellent and very professional”



Conclusions

- Thyroid cancer patients undergoing RAI report a high level of information provision
- However, significant patient anxiety remains surrounding radioiodine treatment
- Optimising patient information provision has the potential to allay these fears and improve patient quality of life.



References

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