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People's Experience with Thyroid Disease

Survey Results

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People's Experience with Thyroid Disease

Foreword

This report provides an initial analysis of the data from an online survey on people's experience with thyroid disease which ran between 6 March to 7 April 2023.

The survey is part of a research study on "Labour Market and Wellbeing Implications of Thyroid Disease" carried out by Professors Catia Montagna and Alexandros Zangelidis from the Centre for Labour Market Research ([CeLMR](#)), Department of Economics, of the University of Aberdeen Business School.

The purpose of the survey was to collect information on thyroid patients' experience from the onset of symptoms to diagnosis and treatment and focused on the implications of thyroid disease, before and after diagnosis/treatment, on patients' wellbeing and labour market engagement.

Anonymous statements from comments respondents sent to the research team have been used throughout the report with their prior permission.

Acknowledgements

The help of the British Thyroid Foundation, the Thyroid Trust, Thyroid UK, Thyroid Patient Advocacy UK, Improve Thyroid Treatment Group, and Miscarriage Support (MISS) in circulating the survey through their network is kindly acknowledged. A special thank goes to all the survey participants.

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Executive Summary

Relatively little evidence exists about the impact of thyroid dysfunctions on the wellbeing and labour market outcomes of those affected. Previous work by the authors highlighted how undiagnosed hypothyroidism can widen existing gender disparities in the labour market.

This survey of people with thyroid disorders was carried out to collect information on patients' experience from the onset of symptoms to diagnosis/treatment and on the effects of thyroid disease, before and after diagnosis/treatment, on their wellbeing and labour market engagement.

- It takes on average 4.5 years for a thyroid condition to be diagnosed.
- Thyroid treatment does not appear to be always effective, with symptoms persisting after the start of treatment and with some patients never feeling the benefits of treatment.
- The diagnosis of hypothyroidism takes longer time and people with hypothyroidism have lower levels of satisfaction with treatment.
- Thyroid disease has lasting adverse effects on people's wellbeing and labour market engagement, with only moderate improvements after the start of treatment.
- Patients on average do not feel they are being heard by the medical profession and do not feel involved or empowered during their medical journey.
- Dissatisfaction with involvement and empowerment is greater for patients suffering from hypothyroidism.
- Patients feel more involved and empowered when diagnosis is made by a female consultant.
- Results highlight importance of timely diagnosis and support for patients.

People's Experience with Thyroid Disease

Background

Thyroid disease may have serious implications on individuals' life and working ability. Whilst there is evidence on the impact of other chronic diseases on the wellbeing and labour market outcomes of those affected, comparatively little is known about the implications of thyroid dysfunctions. The research project carried out by economists Catia Montagna and Alexandros Zangelidis contributes to shed light on this important and hitherto neglected aspect.

Thyroid dysfunctions are much more common in women than in men. Hypothyroidism is the most common and especially so in women, where its occurrence is 10 times higher than in men. In light of these stylised facts, in a recently published paper (*Labour Market Implications of Thyroid Dysfunctions*, C. Montagna and A. Zangelidis, *Economics and Human Biology*¹), the researchers conjecture that thyroid dysfunctions can contribute to explain female/men differences in key labour market outcomes. Using UK data for a ten-year period (2009-2018) the paper supports this conjecture and shows that, compared with women who do not suffer from thyroid disease, women with undetected hypothyroidism are estimated to experience an additional 5% wage penalty over a 'base' female/men wage gap of around 13%. However, the diagnosis of the condition (and presumably the start of treatment) wipes out this additional wage penalty and improves women's employment probability. The improvement of wages seems to be gradual, with wages gains progressively

increasing over time, and exceeding 10% four years after diagnosis. These findings highlight another potential explanation of the gender wage gap, hitherto overlooked in the literature. They also have important implications for public health, as they suggest that potential productivity gains may be achieved through the early detection (and treatment) of thyroid dysfunctions.

The survey that forms the basis for this report was motivated by the realisation that data about thyroid patients' experience is very much patchy and limited. Its aim was to begin to fill this void and help understanding of patients' experience in relation to their diagnosis and treatment, their relationship with the healthcare professionals, and the effects of thyroid conditions on their wellbeing and labour market engagement. The authors are fully aware that the survey could not capture the complexity of the health and wellbeing implications and the individual circumstances of thyroid sufferers' experience. However, its findings will hopefully contribute to

- draw the attention of the medical profession and policymakers to the nature and the consequences of the problems encountered by thyroid patients (even after the start of treatment),
- inform relevant healthcare policy debates and initiatives, and
- inform directions for further research on what we think is a very important public health matter.

¹ <https://doi.org/10.1016/j.ehb.2023.101247>

The survey

The "People's experience with thyroid disease" survey is a national online survey conducted over a month (6 March to 7 April 2023). The survey was fully anonymous and was circulated via the British Thyroid Foundation, the Thyroid Trust, Thyroid UK, Thyroid Patient Advocacy UK, Improve Thyroid Treatment Group, and Miscarriage Support (MISS). Participants had to be UK residents, aged 18 or above and diagnosed with a thyroid condition. Participation in the survey was voluntary and individuals could withdraw from the study at any time during survey completion and were free to omit any question. A total number of 1,176 people participated in the survey.

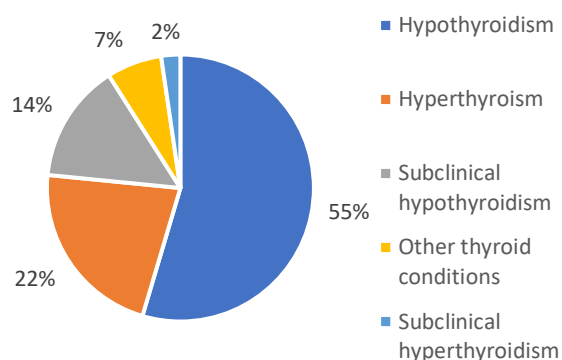
Respondents' profile

Around 95% of the respondents were women², which is consistent with the evidence of a high prevalence of the disease among women. People aged 18 to 88 participated in the survey, with the average age being 53. Almost three quarters of the people were married or living with a partner, and 60% did not have children living in the household. 65% of the respondents had University education (undergraduate or postgraduate degree), around 60% were working (either employed, part-time or full-time, or self-employed) and almost 25% were retired. Most respondents were based in England (82%), followed by people in Scotland (12%), Wales (3.4%) and N. Ireland (2.6%)

The majority of respondents suffered from underactive thyroid, hypothyroid, (69%), followed by 24% people with overactive thyroid, hyperthyroid, and the remaining 7% with other thyroid conditions.

Autoimmune disorders seem to be the key driver both for hypothyroidism (Hashimoto's disease) and hyperthyroidism (Graves' disease). In addition, 20% of all cases of underactive thyroid were subclinical cases, whereas for overactive thyroid the subclinical cases were around 10%.

Thyroid conditions diagnosed



Thyroid conditions	%
Underactive thyroid	69
<i>Hashimoto's disease</i>	34
<i>Non autoimmune hypothyroidism</i>	16
<i>Hypothyroidism (unclassified)</i>	5
<i>Subclinical hypothyroidism</i>	14
Overactive thyroid	24
<i>Graves' disease</i>	20
<i>Non autoimmune hyperthyroidism</i>	1
<i>Hyperthyroidism (unclassified)</i>	1
<i>Subclinical hyperthyroidism</i>	2
Other thyroid conditions	7
<i>Thyroid cancer</i>	6
<i>Goitre</i>	1

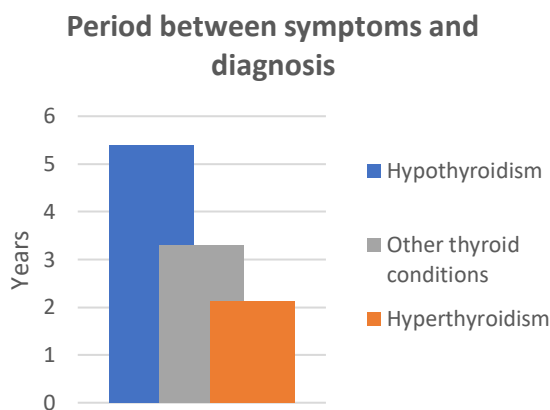
² Due to the small number of male respondents, it is not possible to explore gender differences.

The "journey" from symptoms to diagnosis and treatment

Key points:

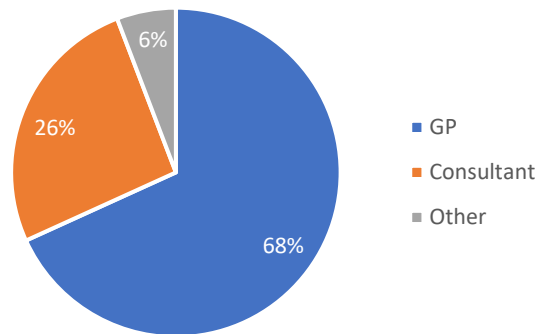
- It takes considerable time for a thyroid condition to be diagnosed
- Thyroid treatment may not be effective
- The diagnosis of hypothyroidism takes longer time and people with hypothyroidism have lower levels of satisfaction with treatment

Thyroid conditions were diagnosed, on average, around four and a half years after the onset of symptoms, and in most cases (almost two thirds of the respondents) it took multiple visits with the healthcare professionals and a worsening of the severity of the symptoms (this is the case for three quarters of the respondents) until diagnosis was made. Furthermore, there are important differences in the timing of diagnosis depending on the type of thyroid condition, with the diagnosis of hypothyroidism taking twice as long, on average, as the diagnosis of hyperthyroidism.



In most of the cases diagnosis was done by a GP (68%), with only 26% of the cases diagnosed by a consultant, and 6% by 'other' healthcare professionals. However, there are no differences in the time of diagnosis, regardless of who did the diagnosis.

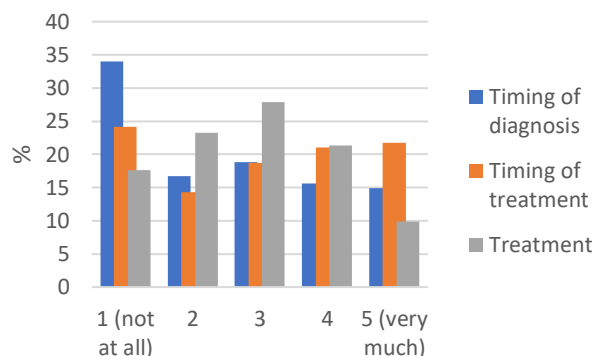
Who did the diagnosis



“ I was diagnosed with thyroid cancer after almost 10 years of being told symptoms were nothing and that it was all in my mind.”

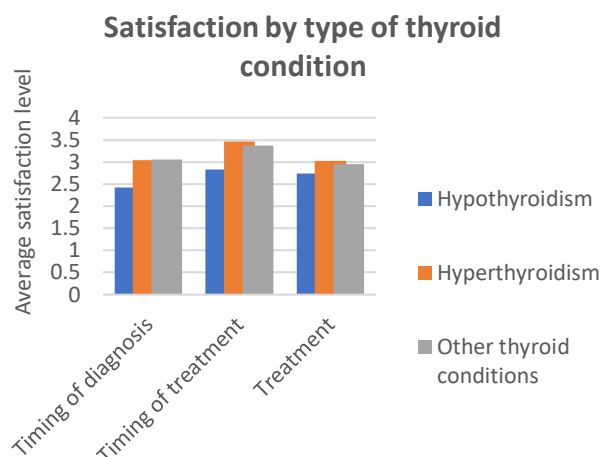
The majority (97%) of people who were diagnosed with a thyroid condition were given treatment. Treatment seems to follow soon after diagnosis, on average within approximately four months from the time of diagnosis.

Satisfaction with



The notable delays between the onset of symptoms and diagnosis are reflected in the reported level of satisfaction with the

timing of diagnosis, with one third of the respondents being “not at all” satisfied. On the other hand, satisfaction with the timing of treatment is higher, which is expected given that in most cases there were no significant delays reported.

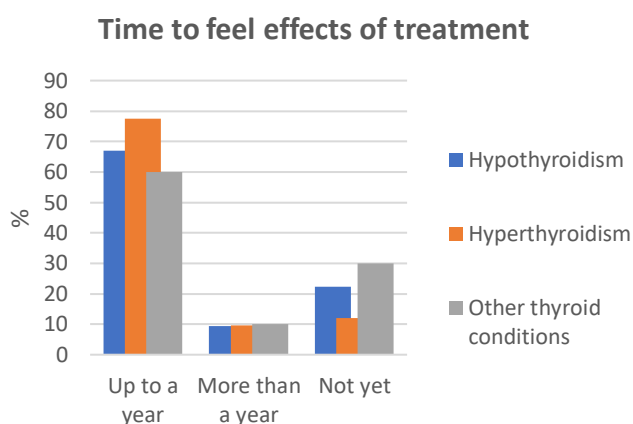


The level of satisfaction with the timing of diagnosis and treatment differs depending on the type of thyroid condition diagnosed, with those suffering with hypothyroidism reporting the lowest levels of satisfaction. This may be explained by the fact that the diagnosis of hypothyroidism on average takes more time (twice compared to hyperthyroidism) from the time that related symptoms appeared.

The majority of the respondents (72%) received just one type of treatment. Reflecting the dominance of hypothyroidism, the most popular type of treatment is thyroid hormone replacement therapy (75.5% of patients), followed by anti-thyroid medicine (22.6% of patients). Most of the respondents currently continue to receive treatment (95%), out of which 71% have regular reviews in their treatment.

However, there are issues raised regarding the effectiveness of treatment. 92% of respondents reported that they still

experience symptoms. Importantly, around 20% of the respondents reported that they have not yet felt the effects of treatment, and this does not appear to be driven by newly treated people. This may explain the relatively low levels of satisfaction with the treatment, with 18% reporting “not at all” satisfied and less than 10% being “very much” satisfied. This is driven predominantly by people with hypothyroidism that seemed to take longer to feel the effects of the treatment compared to hyperthyroidism patients. Specifically, over 20% of hypothyroidism patients have not yet felt the effects of treatment, which is almost twice as the equivalent fraction of hyperthyroid patients. This may explain the disparities in the level of satisfaction with treatment we observe between hypothyroidism and hyperthyroidism patients.



Why does it matter?

The sooner patients feel the effects of treatment, the greater the improvement they likely experience on wellbeing and work.

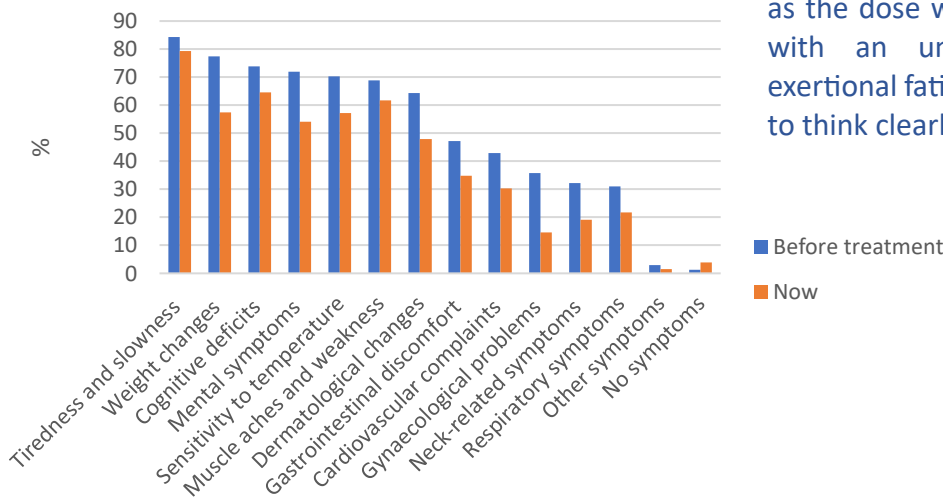
Post-treatment experience

Key points:

- Thyroid symptoms persist after treatment
- Although people's wellbeing, and labour market engagement and prospects improve after treatment, the improvement is moderate, especially for the latter

The symptoms seem to persist even after the start of treatment. The majority of respondents (over 90%) still experience multiple symptoms related to their thyroid conditions, with the most frequent symptoms reported being: tiredness and slowness (79%), cognitive deficits (64%), muscle aches and weakness (62%), weight changes and sensitivity to temperature (57%) and mental symptoms (54%).

Nature of symptoms

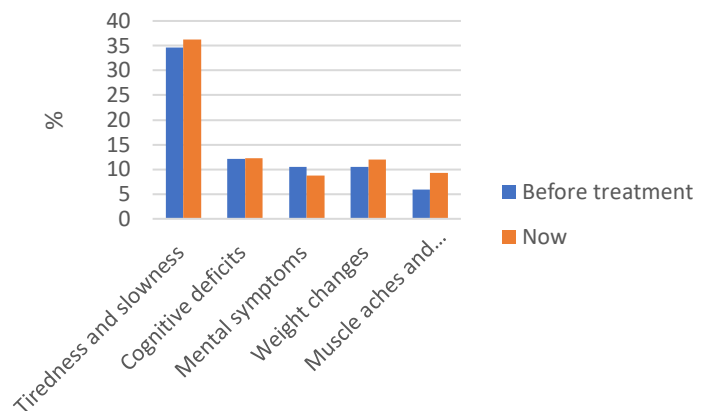


Of the symptoms reported, tiredness and slowness appear to be the most severe (as reported by around 35% of the respondents), followed by cognitive deficits and weight changes (slightly over 10%), and mental symptoms and muscle

aches and weakness (around 10%), with very little improvement observed in the period before the start of treatment and now.

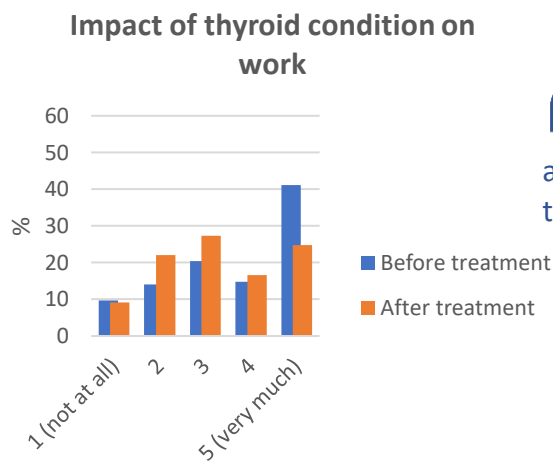
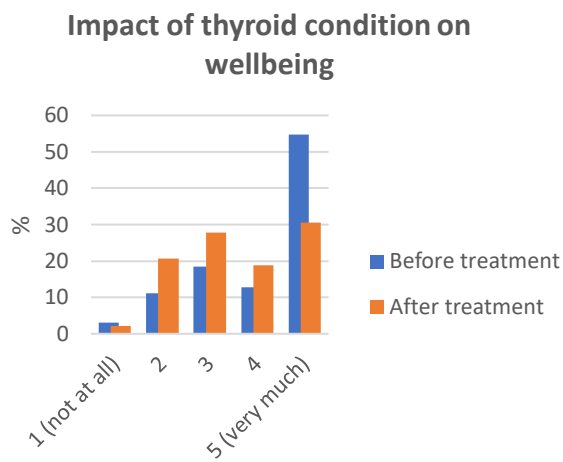
It is therefore evident that diagnosis and the start of the treatment are not the end of patients' journey.

Top 5 most severe symptoms



“ My ability to function did improve overall by about 75% over the first 18 months as the dose was titrated. However, I was left with an unresolved symptom of post exertional fatigue that would leave me unable to think clearly or function physically...”

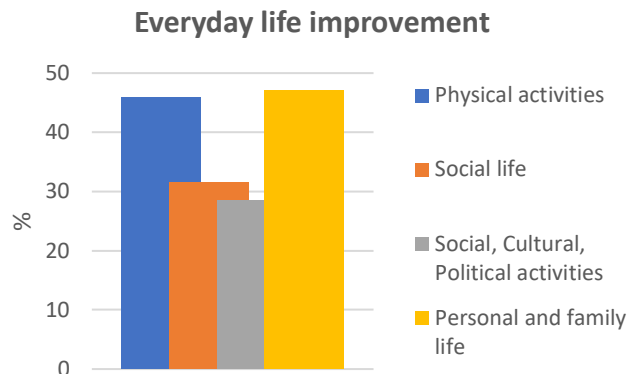
The persistence of symptoms may explain why the thyroid condition appears to continue having an adverse effect on people's wellbeing and work, even after the start of treatment, despite some improvement reported after the start of treatment. Around 30% and 25% of the respondents have reported that after treatment the thyroid condition still affects "very much" their everyday life/wellbeing, and work, respectively.



Various aspects of everyday life have improved after the start or treatment, with 46% people engaging in more physical activities, 32% having a more active social life, 28% engaging more in active social/cultural/political activities, and 47%

enjoying a more rewarding personal and/or family life.

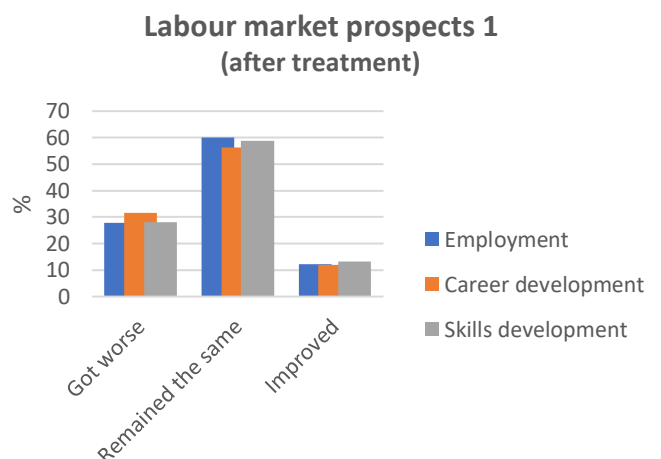
“Neither of my children had a ‘good enough’ level of input from me (a single parent) during this time, until I was eventually diagnosed.”



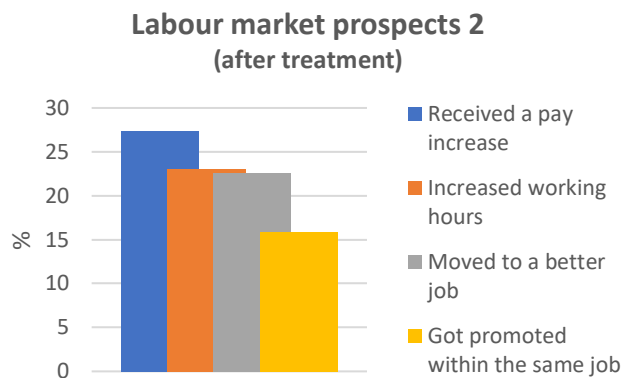
The improvement reported across aspects of labour market engagement (such as employment prospects, career and skill development opportunities) post treatment is more limited. Only around 10% of the respondents reported an improvement, whereas for the majority of

“I was self-employed and it was like walking through treacle everyday.”

people, around 60%, there was no improvement, and for the remaining, around 30%, things even got worse.



In addition, about a quarter (around 25%) only of the respondents experienced an improvement in labour market prospects such as moving to a better job, receiving a pay increase or increasing working hours, and a 15% of respondents got promoted within the same job.



Around three quarters (78%) of the respondents who were employed at the time of diagnosis informed their employer about their thyroid condition. In 23% of these cases, the employer did not appear to be sympathetic at all.

“ I never felt at any time that my employer would've been sympathetic to my difficulties because of my thyroid condition. I took voluntary redundancy aged 44 as I could no longer cope with my job as a university lecturer because of my thyroid condition. I lost my profession, my income, and this has subsequently affected my state and occupational pensions adversely.”

“ I personally suffered having to give up my career and settle for something that was much less than I was capable of, had I been treated more effectively.”



Why does it matter?

When employers are informed of and more sympathetic to the fact that their employees suffer from a thyroid condition, the impact of the condition (after treatment) on work is less.

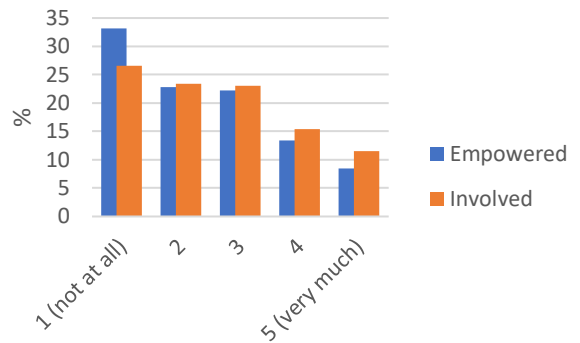
Patient-doctor relationship

Key points:

- Patients did not feel they were heard enough by healthcare professionals
- People felt more involved and empowered when diagnosis was made by a female consultant
- Hypothyroidism patients felt less involved and empowered than patients with hyperthyroidism and other types of thyroid conditions

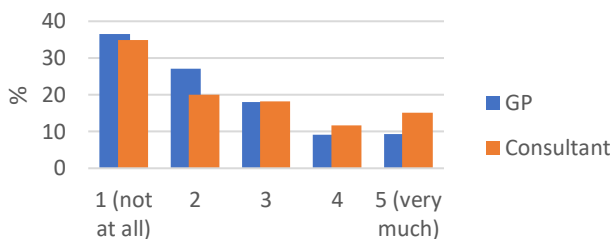
Although there is overall greater level of satisfaction with consultants, with 15% of patients reporting being heard “very much” by consultants and less than 10% by GPs, more than 1/3 of the respondents felt that they have not been heard at all by either a GP or a consultant.

Involvement and Empowerment

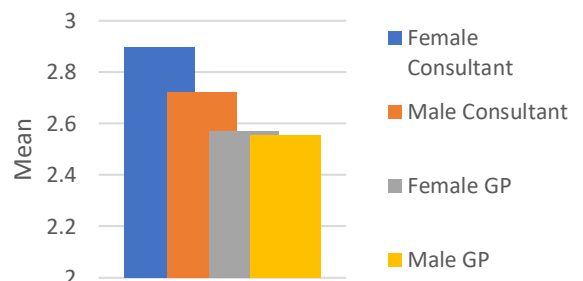


The gender of the health professional who did the diagnosis seems to matter. For 60% of the respondents, diagnosis was done by a male doctor (40% GPs and 20% consultants) and the remaining 40% from female doctors (32% GPs and 8% consultants). People felt more involved and empowered when diagnosis was made by a female consultant.

Heard by



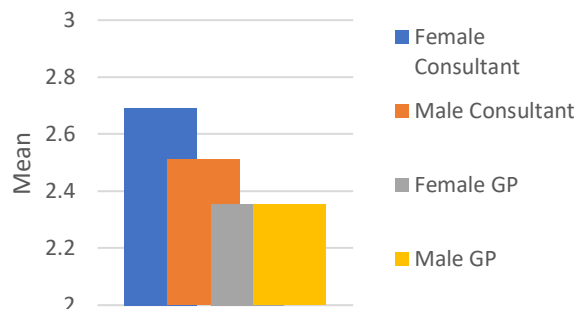
Involved



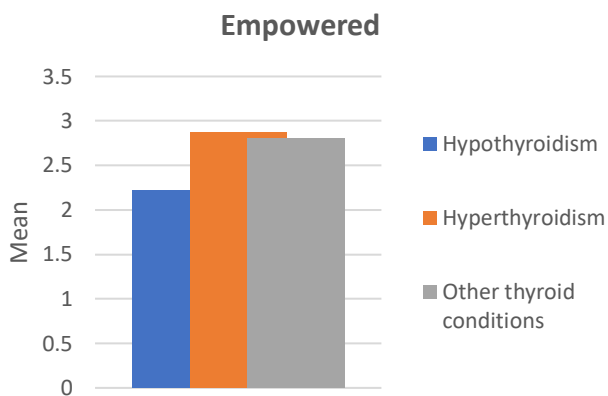
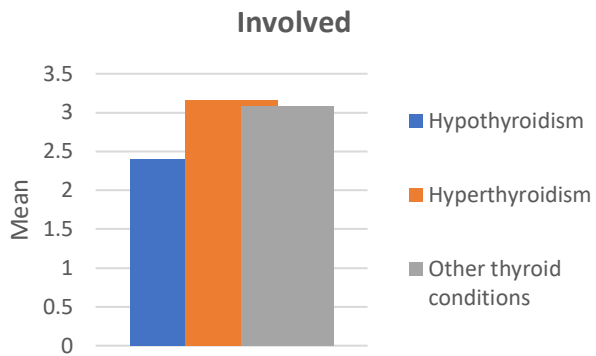
I was told ‘your thyroid is fixed now, it must be something else’.

The majority of people also did not feel they were involved when decisions were made regarding their treatment or empowered and comfortable enough to be able to have an input when decisions were made regarding their thyroid condition.

Empowered



Furthermore, people with hypothyroidism felt less involved and empowered compared to patients suffering from hyperthyroidism or other thyroid conditions.



“ Meanwhile my self-esteem and mental health took a battering...it's really not good for your head when the Doctor infers '*there is nothing physically wrong with you, maybe you're depressed*', but your body just isn't working properly anymore, you know it, and you know you are not depressed.”

Why does it matter?

The improvement in everyday life and wellbeing, and work is greater for the individuals who felt more involved or empowered.

Conclusions and policy implications

The evidence that emerges from this survey confirms that thyroid diseases have serious implications for the life of patients, with adverse and long-lasting consequences on their wellbeing and their ability to engage with and interact with social activities and work³.

Whilst by construction the survey was not suited to reveal a fine resolution of the problems encountered by patients, there are key stylised facts that emerge from its analysis:

- It takes considerable time for a thyroid condition to be diagnosed, in particular for hypothyroidism.
- Thyroid treatment does not appear to be always effective, with symptoms persisting after the start of treatment.
- Thyroid disease has lasting adverse effects on people's wellbeing and labour market engagement, with only moderate improvements after the start of treatment.
- Patients on average do not feel they are being heard by the medical profession and do not feel empowered during their medical journey. Whilst this is particularly true for patients suffering from hypothyroidism, satisfaction is higher when diagnosis is made by a female consultant.

This evidence should draw the attention of the medical profession and policymakers to the nature and the consequences of the problems encountered by thyroid patients (even after the start of treatment) and inform relevant healthcare policy debates and initiatives.

What can be done?

- Raise awareness on wellbeing and labour market implications of thyroid dysfunctions
- Emphasise the importance of early diagnosis
- Review the effectiveness of treatment
- Establish a UK-wide "thyroid" taskforce to investigate how people with thyroid dysfunctions can be better supported
- Include thyroid conditions in the Women's Health plan (England and Scotland)
- Increase awareness of healthcare professionals on women's health issues
- Develop workplace and HR policies on organisations' approach to staff experiencing thyroid-related symptoms, and what support those employees can expect to receive

³ The survey results presented in the report are also confirmed by regression analysis.