Appendix E – Full Survey Results

1. Age

- 18 30 (6.57%, n=282)
- 31 45 (33.39%, n=1,433)
- 46 60 (42.08%, n=1,806)
- 60+ (17.96%, n=771)

2. Gender

- Male (4.63%, n=198)
- Female (94.91%, n=4,062)
- Transgender (0.47%, n=20)
- 3. These are the symptoms most commonly associated with hypothyroidism. Have you had/got any of these symptoms?

Fatigue Cold intolerance

Menstrual changes Dry skin

Fertility problems
Appetite changes
Weight gain
Aches and pains
Sleep changes
Dry skin
Hair changes
Voice changes
Poor motor skills
Poor co-ordination
Fluid retention

Constipation Swelling

- Yes (99.56%, n=4,272)
- No (0.44%, n=19)
- 4. Have you had an OFFICIAL diagnosis of hypothyroidism from a qualified medical doctor?
 - Yes (92.65%, n=3,983)
 - No (7.35%, n=316)
- 5. Before you were diagnosed with hypothyroidism how did your HYPOTHYROID symptoms make you feel? Please rate: 1 = Worst I have ever felt in my life and 10 = Felt really well (no hypothyroid symptoms prior to diagnosis)
 - 1 (31.85%, n=1,270)
 - 2 (14.92%, n=595)
 - 3 (19.46%, n=776)
 - 4 (8.38%, n=334)
 - 5 (7.85%, n=313)
 - 6 (3.06%, n=122)
 - 7 (3.61%, n=144)
 - 8 (4.01%, n=160)
 - 9 (2.48%, n=99)
 - 10 (4.36%, n=174)

- 6. How long after you started to have hypothyroid symptoms were you diagnosed with hypothyroidism and how did you feel about the amount of time it took to diagnose you? Please tick only one option. Please rate: 1 = Unhappy with the time it took 10 = Happy with the time it took
 - 1 6 months
 - 1 (11.69%, n=163)
 - 2 (3.30%, n=46)
 - 3 (5.74%, n=80)
 - 4 (5.38%, n=75)
 - 5 (10.90%, n=152)
 - 6 (7.25%, n=101)
 - 7 (10.11%, n=141)
 - 8 (11.12%, n=155)
 - 9 (7.68%, n=107)
 - 10 (26.83%, n=374)
 - 7 12 months
 - 1 (31.26%, n=171)
 - 2 (10.97%, n=60)
 - 3 (12.61%, n=69)
 - 4 (9.14%, n=50)
 - 5 (12.61%, n=69)
 - 6 (4.94%, n=27)
 - 7 (5.85%, n=32)
 - 8 (3.84%, n=21)
 - 9 (2.93%, n=16)
 - 10 (5.85%, n=32)
 - 1 5 years
 - 1 (56.34%, n=640)
 - 2 (9.86%, n=113)
 - 3 (10.39%, n=118)
 - 4 (5.63%, n=64)
 - 5 (6.87%, n=78)
 - 6 (2.29%, n=26)
 - 7 (2.46%, n=28)
 - 8 (2.38%, n=27)
 - 9 (1.32%, n=14)
 - 10 (2.46%, n=28)
 - 5 10 years
 - 1 (71.15%, n=333)
 - 2 (6.62%, n=31)
 - 3 (5.77%, n=27)
 - 4 (3.85%, n=18)
 - 5 (3.85%, n=18)
 - 6 (1.92%, n=9)
 - 7 (1.92%, n=9)
 - 8 (0.64%, n=3)
 - 9 (1.07%, n=5)
 - 10 (3.21%, n=15)

- 10 15 years
 - 1 (76.82%, n=169)
 - 2 (6.82%, n=15)
 - 3 (4.55%, n=10)
 - 4 (1.36%, n=3)
 - 5 (3.64%, n=8)
 - 6 (0.91%, n=2)
 - 7 (1.36%, n=3)
 - 8 (0.45%, n=1)
 - 9 (1.36%, n=3)
 - 10 (2.73%, n=6)
- More than 15 years
 - 1 (77.39%, n=178)
 - 2 (2.17%, n=5)
 - 3 (2.17%, n=5)
 - 4 (2.61%, n=6)
 - 5 (3.91%, n=9)
 - 6 (0.87%, n=2)
 - 7 (2.61%, n=6)
 - 8 (1.74%, n=4)
 - 9 (1.30%, n=3)
 - 10 (5.22%, n=12)
- Other (please specify) (n=266)
- 7. Approximately how many times did you visit your GP with symptoms of hypothyroidism BEFORE you were given a diagnosis of hypothyroidism?
 - 0 (9.31%, n=371)
 - 1 (14.51%, n=578)
 - 2 5 (29.90%, n=1,191)
 - 6 -10 (17.25%, n=687)
 - 11 20 (10.02%, n=399)
 - 20 50 (6.65%, n=265)
 - 50+ (2.66%, n=106)
 - Can't remember (9.69%, n=386)
- 8. Were you prescribed any medications (excluding thyroid medications) for your symptoms BEFORE your diagnosis of hypothyroidism?
 - Yes (28.52%, n=1,136)
 - No (71.48%, n=2,847)

- 9. What medications were you prescribed for your symptoms BEFORE your diagnosis of hypothyroidism and how much did they improve your hypothyroid symptoms? Please rate: 1 = Not at all and 10 = completely improved my hypothyroid symptoms
 - Antidepressants
 - 1 (61.07%, n=480)
 - 2 (12.47%, n=98)
 - 3 (10.81%, n=85)
 - 4 (3.94%, n=31)
 - 5 (6.62%, n=52)
 - 6 (2.04%, n=16)
 - 7 (0.89%, n=7)
 - 8 (0.13%, n=1)
 - 9 (0.25%, n=2)
 - 10 (1.78%, n=14)
 - Proton pump inhibitors (to reduce stomach acid)
 - 1 (60.85%, n=143)
 - 2 (10.21%, n=24)
 - 3 (8.94%, n=21)
 - 4 (5.11%, n=12)
 - 5 (6.38%, n=15)
 - 6 (2.13%, n=5)
 - 7 (2.13%, n=5)
 - 8 (1.28%, n=3)
 - 9 (0.85%, n=2)
 - 10 (2.13%, n=5)
 - Painkillers
 - 1 (48.50%, n=227)
 - 2 (16.67%, n=78)
 - 3 (14.32%, n=67)
 - 4 (8.33%, n=39)
 - 5 (6.84%, n=32)
 - 6 (0.64%, n=3)
 - 7 (1.50%, n=7)
 - 8 (0.64%, n=3)
 - 9 (0.43%, n=2)
 - 10 (2.14%, n=10)
 - Statins (to lower cholesterol)
 - 1 (73.45%, n=83)
 - 2 (5.31%, n=6)
 - 3 (6.19%, n=7)
 - 4 (5.31%, n=6)
 - 5 (5.31%, n=6)
 - 6 (0.88%, n=1)
 - 7 (1.77%, n=2)
 - 8 (0.88%, n=1)
 - 9 (0.00%, n=0)
 - 10 (0.88%, n=1)

- HRT (for menopause)
 - 1 (61.93%, n=122)
 - 2 (11.68%, n=23)
 - 3 (11.17%, n=22)
 - 4 (4.06%, n=8)
 - 5 (3.05%, n=6)
 - 6 (2.03%, n=4)
 - 7 (2.54%, n=5)
 - 8 (0.00%, n=0)
 - 9 (0.51%, n=1)
 - 10 (3.05%, n=6)
- Beta Blockers (to reduce heart rate)
 - 1 (56.07%, n=134)
 - 2 (10.04%, n=24)
 - 3 (11.30%, n=27)
 - 4 (8.37%, n=20)
 - 5 (7.53%, n=18)
 - 6 (1.26%, n=3)
 - 7 (1.67%, n=4)
 - 8 (0.42%, n=1)
 - 9 (0.42%, n=1)
 - 10 (2.93%, n=7)
- Tranquilisers (for anxiety)
 - 1 (60.99%, n=136)
 - 2 (13.90%, n=31)
 - 3 (8.97%, n=20)
 - 4 (4.93%, n=11)
 - 5 (4.93%, n=11)
 - 6 (2.24%, n=5)
 - 7 (1.35%, n=3)
 - 8 (0.45%, n=1)
 - 9 (0.90%, n=2)
 - 10 (1.35%, n=3)
- Medications for psychosis
 - 1 (74.70%, n=62)
 - 2 (9.64%, n=8)
 - 3 (4.82%, n=4)
 - 4 (1.20%, n=1)
 - 5 (2.41%, n=2)
 - 6 (2.41%, n=2)
 - 7 (0.00%, n=0)
 - 8 (3.61%, n=3)
 - 9 (0.00%, n=0)
 - 10 (1.20%, n=1)

- · Medications for stabilizing mood
 - 1 (66.89%, n=99)
 - 2 (13.51%, n=20)
 - 3 (8.78%, n=13)
 - 4 (3.38%, n=5)
 - 5 (2.03%, n=3)
 - 6 (1.35%, n=2)
 - 7 (0.68%, n=1)
 - 8 (1.35%, n=2)
 - 9 (0.00%, n=0)
 - 10 (2.03%, n=3)
- Medications for high blood pressure
 - 1 (60.00%, n=90)
 - 2 (9.33%, n=14)
 - 3 (10.00%, n=15)
 - 4 (5.33%, n=8)
 - 5 (8.00%, n=12)
 - 6 (2.67%, n=4)
 - 7 (1.33%, n=2)
 - 8 (0.00%, n=0)
 - 9 (1.33%, n=2)
 - 10 (2.00%, n=3)
- Nifedipene (for Raynaud's phenomenon)
 - 1 (81.82%, n=36)
 - 2 (6.82%, n=3)
 - 3 (0.00%, n=0)
 - 4 (0.00%, n=0)
 - 5 (4.55%, n=2)
 - 6 (2.27%, n=1)
 - 7 (0.00%, n=0)
 - 8 (0.00%, n=0)
 - 9 (2.27%, n=1)
 - 10 (2.27%, n=1)
- Sleeping tablets
 - 1 (56.06%, n=148)
 - 2 (16.29%, n=43)
 - 3 (12.50%, n=33)
 - 4 (4.55%, n=12)
 - 5 (5.68%, n=15)
 - 6 (1.89%, n=5)
 - 7 (1.14%, n=3)
 - 8 (1.14%, n=3)
 - 9 (0.00%, n=0)
 - 10 (0.76%, n=2)

- Steroids tablets, creams or injections (for arthritis/joint pain)
 - 1 (50.00%, n=104)
 - 2 (11.06%, n=23)
 - 3 (12.02%, n=25)
 - 4 (10.10%, n=21)
 - 5 (7.69%, n=16)
 - 6 (1.44%, n=3)
 - 7 (1.44%, n=3)
 - 8 (1.92%, n=4)
 - 9 (2.40%, n=5)
 - 10 (1.92%, n=4)

Anticonvulsants

- 1 (77.78%, n=42)
- 2 (7.41%, n=4)
- 3 (7.41%, n=4)
- 4 (1.85%, n=1)
- 5 (1.85%, n=1)
- 6 (1.85%, n=1)
- 7 (1.85%, n=1)
- 8 (0.00%, n=0)
- 9 (0.00%, n=0)
- 10 (0.00%, n=0)

Laxatives

- 1 (57.63%, n=136)
- 2 (11.44%, n=27)
- 3 (11.02%, n=26)
- 4 (6.78%, n=16)
- 5 (8.47%, n=20)
- 6 (0.85%, n=2)
- 7 (0.85%, n=2)
- 8 (0.42%, n=1)9 (0.42%, n=1)
- 10 (2.12%, n=5)

Dry skin treatments

- 1 (46.03%, n=139)
- 2 (14.57%, n=44)
- 3 (13.25%, n=40)
- 4 (9.60%, n=29)
- 5 (6.62%, n=20)
- 6 (2.32%, n=7)
- 7 (2.65%, n=8)
- 8 (1.32%, n=4)
- 9 (1.32%, n=4)
- 10 (2.32%, n=7)

Asthma inhaler

- 1 (51.10%, n=116)
- 2 (11.89%, n=27)
- 3 (11.01%, n=25)
- 4 (7.05%, n=16)
- 5 (9.69%, n=22)
- 6 (3.08%, n=7)
- 7 (1.32%, n=3)
- 8 (0.88%, n=2)
- 9 (0.88%, n=2)
- 10 (3.08%, n=7)

Antihistamines

- 1 (52.42%, n=130)
- 2 (13.71%, n=34)
- 3 (9.68%, n=24)
- 4 (6.45%, n=16)
- 5 (7.66%, n=19)
- 6 (3.23%, n=8)
- 7 (2.42%, n=6)
- 8 (0.81%, n=2)
- 9 (1.21%, n=3)
- 10 (2.42%, n=6)

· Medications for dry eyes

- 1 (46.55%, n=108)
- 2 (9.91%, n=23)
- 3 (12.50%, n=29)
- 4 (6.03%, n=14)
- 5 (12.50%, n=29)
- 6 (4.31%, n=10)
- 7 (2.59%, n=6)
- 8 (1.72%, n=4)
- 9 (0.43%, n=1)
- 10 (3.45%, n=8)

Other medications

- 1 (56.49%, n=209)
- 2 (10.27%, n=38)
- 3 (10.00%, n=37)
- 4 (5.95%, n=22)
- 5 (6.76%, n=25)
- 6 (3.24%, n=12)
- 7 (1.89%, n=7)
- 8 (0.81%, n=3)
- 9 (0.81%, n=3)
- 10 (3.78%, n=14)

10. What were you told is the cause of your hypothyroidism?

- Congenital hypothyroidism (2.21%, n=88)
- Thyroidectomy (4.52%, n=180)
- Radio Active Iodine treatment (3.94%, n=157)
- Thyroid cancer (1.56%, n=62)
- Hashimoto's disease (autoimmune) (16.95%, n=675)
- Hypopituitarism (0.55%, n=22)
- I wasn't told the cause of my hypothyroidism (64.47%, n=2,568)
- Other (please specify) (5.80%, n=231)

11. Who FIRST diagnosed your hypothyroidism?

- NHS GP (70.70%, n=2,816)
- Private GP (4.44%, n=177)
- NHS Endocrinologist or Consultant (10.75%, n=428)
- Private Endocrinologist or Consultant (4.80%, n=191)
- Other (please specify) (9.31%, n=371)

12. Were you diagnosed with any other conditions BEFORE your diagnosis of hypothyroidism?

- Yes (46.20%, n=1,840)
- No (53.80%, n=2,143)

13. What other condition(s)?

- Fibromyalgia (previously known as fibrositis) (12.85%, n=268)
- Depression (50.72%, n=1,058)
- ME/CFS (12.85%, n=268)
- Diabetes (4.03%, n=84)
- Gastritis (9.16%, n=191)
- Interstitial cystitis (3.31%, n=69)
- Infertility (7.14%, n=149)
- Rheumatoid arthritis (4.79%, n=100)
- Osteoarthritis (10.55%, n=220)
- Hypercholesterolemia (high cholesterol) (10.02%, n=209)
- Menopause (17.64%, n=368)
- Hypertension (high blood pressure) (13.37%, n=279)
- Heart problems (6.42%, n=134)
- Osteopenia/Osteoporosis (4.31%, n=90)
- Other (please specify) (50.72%, n=1,058)

- 14. What medications were you on for these conditions and what effect did these medications have on your symptoms? Please rate all applicable medications: 1 = No effect and 10 = Relieved symptoms completely
 - None
 - 1 (89.76%, n=377)
 - 2 (0.95%, n=4)
 - 3 (1.67%, n=7)
 - 4 (0.95%, n=4)
 - 5 (2.62%, n=11)
 - 6 (0.24%, n=1)
 - 7 (0.95%, n=4)
 - 8 (0.48%, n=2)
 - 9 (0.00%, n=0)
 - 10 (2.38%, n=10)
 - Painkillers
 - 1 (30.76%, n=211)
 - 2 (17.20%, n=118)
 - 3 (15.31%, n=105)
 - 4 (9.62%, n=66)
 - 5 (12.68%, n=87)
 - 6 (5.83%, n=40)
 - 7 (4.08%, n=28)
 - 8 (2.04%, n=14)
 - 9 (1.46%, n=10)
 - 10 (1.02%, n=7)
 - Antidepressants
 - 1 (40.81%, n=402)
 - 2 (15.03%, n=148)
 - 3 (14.82%, n=146)
 - 4 (7.61%, n=75)
 - 5 (11.17%, n=110)
 - 6 (4.16%, n=41)
 - 7 (2.84%, n=28)
 - 8 (1.83%, n=18)
 - 9 (0.81%, n=8)
 - 10 (0.91%, n=9)
 - Metformin
 - 1 (54.93%, n=78)
 - 2 (8.45%, n=12)
 - 3 (8.45%, n=12)
 - 4 (7.04%, n=10)
 - 5 (10.56%, n=15)
 - 6 (3.52%, n=5)
 - 7 (2.82%, n=4)
 - 8 (3.52%, n=5)
 - 9 (0.00%, n=0)
 - 10 (0.70%, n=1)

- Proton pump inhibitors (to reduce stomach acid)
 - 1 (44.64%, n=100)
 - 2 (8.93%, n=20)
 - 3 (8.48%, n=19)
 - 4 (4.02%, n=9)
 - 5 (10.27%, n=23)
 - 6 (4.91%, n=11)
 - 7 (5.36%, n=12)
 - 8 (6.70%, n=15)
 - 9 (2.68%, n=6)
 - 10 (4.02%, n=9)

Antibiotics

- 1 (49.47%, n=141)
- 2 (10.88%, n=31)
- 3 (11.93%, n=34)
- 4 (8.07%, n=23)
- 5 (8.42%, n=24)
- 6 (2.81%, n=8)
- 7 (2.81%, n=8)
- 8 (2.11%, n=6)
- 9 (0.70%, n=2)
- 10 (2.81%, n=8)

Medications for infertility

- 1 (72.07%, n=80)
- 2 (6.31%, n=7)
- 3 (3.60%, n=4)
- 4 (1.80%, n=2)
- 5 (3.60%, n=4)
- 6 (0.90%, n=1)
- 7 (2.70%, n=3)8 (2.70%, n=3)
- 9 (0.90%, n=1)
- 10 (5.41%, n=6)
- Steroids tablets, creams or injections (for arthritis/joint pain)
 - 1 (37.82%, n=104)
 - 2 (9.09%, n=25)
 - 3 (13.45%, n=37)
 - 4 (10.18%, n=28)
 - 5 (8.73%, n=24)
 - 6 (4.36%, n=12)
 - 7 (4.36%, n=12)
 - 8 (5.45%, n=15)
 - 9 (2.55%, n=7)
 - 10 (4.00%, n=11)

- Calcium for osteoporosis
 - 1 (52.11%, n=74)
 - 2 (7.04%, n=10)
 - 3 (9.15%, n=13)
 - 4 (9.15%, n=13)
 - 5 (9.15%, n=13)
 - 6 (5.63%, n=8)
 - 7 (2.11%, n=3)
 - 8 (2.11%, n=3)
 - 9 (1.41%, n=2)
 - 10 (2.11%, n=3)
- Statins (to lower cholesterol)
 - 1 (56.37%, n=115)
 - 2 (6.37%, n=13)
 - 3 (8.33%, n=17)
 - 4 (4.41%, n=9)
 - 5 (8.33%, n=17)
 - 6 (2.94%, n=6)
 - 7 (2.45%, n=5)
 - 8 (4.90%, n=10)
 - 9 (1.96%, n=4)
 - 10 (3.92%, n=8)
- HRT (for menopause)
 - 1 (49.09%, n=135)
 - 2 (9.09%, n=25)
 - 3 (12.00%, n=33)
 - 4 (9.09%, n=25)
 - 5 (7.64%, n=21)
 - 6 (1.82%, n=5)
 - 7 (4.36%, n=12)
 - 8 (4.00%, n=11)
 - 9 (0.73%, n=2)
 - 10 (2.18%, n=6)
- Medications for high blood pressure
 - 1 (34.31%, n=105)
 - 2 (7.52%, n=23)
 - 3 (12.75%, n=39)
 - 4 (4.90%, n=15)
 - 5 (14.71%, n=45)
 - 6 (6.21%, n=19)
 - 7 (6.21%, n=19)
 - 8 (7.52%, n=23)
 - 9 (2.61%, n=8)
 - 10 (3.27%, n=10)

- Beta Blockers (to reduce heart rate)
 - 1 (41.51%, n=132)
 - 2 (11.32%, n=36)
 - 3 (12.58%, n=40)
 - 4 (8.81%, n=28)
 - 5 (7.23%, n=23)
 - 6 (5.03%, n=16)
 - 7 (4.09%, n=13)
 - 8 (3.77%, n=12)
 - 9 (2.20%, n=7)
 - 10 (3.46%, n=11)

Sleeping tablets

- 1 (39.08%, n=136)
- 2 (18.10%, n=63)
- 3 (14.66%, n=51)
- 4 (6.90%, n=24)
- 5 (11.21%, n=39)
- 6 (2.87%, n=10)
- 7 (0.86%, n=3)
- 8 (2.30%, n=8)
- 9 (1.44%, n=5)
- 10 (2.59%, n=9)

Other

- 1 (39.92%, n=204)
- 2 (7.63%, n=39)
- 3 (11.74%, n=60)
- 4 (6.46%, n=33)
- 5 (10.37%, n=53)
- 6 (6.26%, n=32)
- 7 (5.68%, n=29)
- 8 (5.09%, n=26)
- 9 (2.15%, n=11)
- 10 (4.70%, n=24)

15. Did you see any NHS specialist clinicians for these conditions i.e. rheumatologist, psychiatrist etc?

- Yes (47.56%, n=985)
- No (52.44%, n=1,086)
- 16. Did you see any PRIVATE specialist clinicians for these conditions i.e. rheumatologist, psychiatrist etc?
 - Yes (18.83%, n=390)
 - No (81.17%, n=1,681)

17. Approximately how much have you spent on seeing private specialists for these other conditions?

- Up to £100 (4.57%, n=18)
- £101 £200 (6.60%, n=26)
- £201 £300 (7.11%, n=28)
- £301 £400 (2.28%, n=9)
- £401 £500 (5.33%, n=21)
- £501 £1000 (13.96%, n=55)
- £1001 £2000 (11.42%, n=45)
- £2001 £5000 (14.97%, n=59)
- More than £5000 (17.01%, n=67)
- I don't know, I didn't keep track (16.75%, n=66)

18. Did you see any COMPLEMENTARY THERAPISTS for these conditions i.e. nutritionist, acupuncturist etc?

- Yes (32.75%, n=678)
- No (67.25%, n=1,392)

19. Approximately how much have you spent on seeing complementary therapists for your OTHER CONDITIONS?

- Up to £100 (8.08%, n=55)
- £101 £200 (7.34%, n=50)
- £201 £300 (8.37%, n=57)
- £301 £400 (6.75%, n=46)
- £401 £500 (7.34%, n=50)
- £501 £1000 (14.39%, n=98)
- £1001 £2000 (13.22%, n=90)
- £2001 £5000 (9.25%, n=63)
- More than £5000 (9.25%, n=63)
- I don't know, I didn't keep track (16.01%, n=109)

20. Was your hypothyroidism diagnosed by thyroid testing?

- Yes (87.56%, n=3,639)
- No (i.e. I had a thyroidectomy) (12.44%, n=517)

21. What thyroid tests were done by your clinician to achieve diagnosis?

- NHS GP
 - TSH (67.73%, n=2,218)
 - FT4 (32.89%, n=1,077)
 - FT3 (14.05%, n=460)
 - Thyroid Peroxidase Antibodies (TPO) (14.11%, n=462)
 - Thyroglobulin Antibodies (TgAb) (6.50%, n=213)
 - FT4/FT3 Urine test (1.19%, n=39)
 - Don't know (32.92%, n=1,078)

- Private GP
 - TSH (56.72%, n=135)
 - FT4 (51.26%, n=122)
 - FT3 (49.16%, n=117)
 - Thyroid Peroxidase Antibodies (TPO) (34.45%, n=82)
 - Thyroglobulin Antibodies (TgAb) (27.31%, n=65)
 - FT4/FT3 Urine test (11.34%, n=27)
 - Don't know (34.87%, n=83)
- NHS Endocrinologist/Consultant
 - TSH (63.80%, n=380)
 - FT4 (46.97%, n=280)
 - FT3 (33.00%, n=196)
 - Thyroid Peroxidase Antibodies (TPO) (25.76%, n=153)
 - Thyroglobulin Antibodies (TgAb) (16.84%, n=100)
 - FT4/FT3 Urine test (5.22%, n=31)
 - Don't know (34.68%, n=206)
- Private Endocrinologist/Consultant
 - TSH (56.77%, n=172)
 - FT4 (52.81%, n=160)
 - FT3 (50.17%, n=152)
 - Thyroid Peroxidase Antibodies (TPO) (40.59%, n=123)
 - Thyroglobulin Antibodies (TgAb) (32.34%, n=98)
 - FT4/FT3 Urine test (9.24%, n=28)
 - Don't know (33.00%, n=100)
- Other Practitioner/Clinician
 - TSH (45.02%, n=113)
 - FT4 (32.27%, n=81)
 - FT3 (29.88%, n=75)
 - Thyroid Peroxidase Antibodies (TPO) (25.10%, n=63)
 - Thyroglobulin Antibodies (TgAb) (18.33%, n=46)
 - FT4/FT3 Urine test (11.16%, n=28)
 - Don't know (45.42%, n=114)

22. Have you ever had thyroid testing refused?

- Yes (26.69%, n=1,124)
- No (73.31%, n=3,087)

23. Which tests were refused by your clinician and why?

NHS GP

- TSH
 - Wasn't given a reason (23.22%, n=88)
 - Not due another test yet (42.48%, n=161)
 - No relevant symptoms (10.55%, n=40)
 - Offered other tests first (5.01%, n=19)
 - Policy of GP surgery/practice (4.75%, n=18)
 - Hypothyroidism guidelines (7.39%, n=28)
 - Cost (1.85%, n=7)
 - Doctor said lab wouldn't do it (3.43%, n=13)
 - Doctor requested and lab didn't do (1.32%, n=5)

FT4

- Wasn't given a reason (23.25%, n=133)
- Not due another test yet (11.54%, n=66)
- No relevant symptoms (5.59%, n=32)
- Offered other tests first (3.67%, n=21)
- Policy of GP surgery/practice (11.54%, n=66)
- Hypothyroidism guidelines (10.14%, n=58)
- Cost (2.45%, n=14)
- Doctor said lab wouldn't do it (21.68%, n=124)
- Doctor requested and lab didn't do (10.14%, n=58)

FT3

- Wasn't given a reason (20.90%, n=178)
- Not due another test yet (3.42%, n=29)
- No relevant symptoms (4.37%, n=37)
- Offered other tests first (2.36%, n=20)
- Policy of GP surgery/practice (13.34%, n=113)
- Hypothyroidism guidelines (9.45%, n=79)
- Cost (2.95%, n=25)
- Doctor said lab wouldn't do it (28.93%, n=245)
- Doctor requested and lab didn't do (14.29%, n=121)

Thyroid Peroxidase Antibodies (TPO)

- Wasn't given a reason (37.12%, n=184)
- Not due another test vet (4.06%, n=20)
- No relevant symptoms (7.30%, n=36)
- Offered other tests first (4.06%, n=20)
- Policy of GP surgery/practice (12.78%, n=63)
- Hypothyroidism guidelines (8.72%, n=42)
- Cost (3.25%, n=16)
- Doctor said lab wouldn't do it (18.66%, n=92)
- Doctor requested and lab didn't do (4.06%, n=20)

- Thyroglobulin Antibodies (TgAb)
 - Wasn't given a reason (41.15%, n=194)
 - Not due another test yet (2.99%, n=14)
 - No relevant symptoms (6.40%, n=30)
 - Offered other tests first (2.77%, n=13)
 - Policy of GP surgery/practice (12.58%, n=59)
 - Hypothyroidism guidelines (9.17%,n=42)
 - Cost (3.20%, n=15)
 - Doctor said lab wouldn't do it (17.48%, n=82)
 - Doctor requested and lab didn't do (4.26%, n=20)

Reverse T3

- Wasn't given a reason (33.82%, n=210)
- Not due another test yet (0.97%, n=6)
- No relevant symptoms (5.34%, n=33)
- Offered other tests first (2.27%, n=14)
- Policy of GP surgery/practice (12.78%, n=79)
- Hypothyroidism guidelines (8.25%, n=50)
- Cost (4.05%, n=25)
- Doctor said lab wouldn't do it (28.96%, n=179)
- Doctor requested and lab didn't do (3.56%, n=22)

DIO2 gene

- Wasn't given a reason (46.43%, n=183)
- Not due another test yet (1.53%, n=6)
- No relevant symptoms (5.87%, n=23)
- Offered other tests first (3.32%, n=13)
- Policy of GP surgery/practice (12.76%, n=50)
- Hypothyroidism guidelines (7.40%, n=28)
- Cost (4.34%, n=17)
- Doctor said lab wouldn't do it (17.35%, n=68)
- Doctor requested and lab didn't do (1.02%, n=4)

Private GP

- TSH
 - Wasn't given a reason (57.14%, n=4)
 - Not due another test yet (14.29%, n=1)
 - No relevant symptoms (14.29%, n=1)
 - Offered other tests first (0.00%, n=0)
 - Policy of GP surgery/practice (0.00%, n=0)
 - Hypothyroidism guidelines (0.00%, n=0)
 - Cost (14.29%, n=1)
 - Doctor said lab wouldn't do it (0.00%, n=0)
 - Doctor requested and lab didn't do (0.00%, n=0)

FT4

- Wasn't given a reason (33.33%, n=2)
- Not due another test yet (0.00%, n=0)
- No relevant symptoms (0.00%, n=0)
- Offered other tests first (0.00%, n=0)
- Policy of GP surgery/practice (16.67%, n=1)
- Hypothyroidism guidelines (16.67%, n=1)
- Cost (16.67%, n=1)
- Doctor said lab wouldn't do it (16.67%, n=1)
- Doctor requested and lab didn't do (0.00%, n=0)

FT3

- Wasn't given a reason (36.36%, n=4)
- Not due another test yet (9.09%, n=1)
- No relevant symptoms (0.00%, n=0)
- Offered other tests first (0.00%, n=0)
- Policy of GP surgery/practice (9.09%, n=1)
- Hypothyroidism guidelines (18.18%, n=2)
- Cost (9.09%, n=1)
- Doctor said lab wouldn't do it (9.09%, n=1)
- Doctor requested and lab didn't do (9.09%, n=1)

Thyroid Peroxidase Antibodies (TPO)

- Wasn't given a reason (25.00%, n=2)
- Not due another test yet (12.50%, n=1)
- No relevant symptoms (12.50%, n=1)
- Offered other tests first (0.00%, n=0)
- Policy of GP surgery/practice (12.50%, n=1)
- Hypothyroidism guidelines (25.00%, n=2)
- Cost (12.50%, n=1)
- Doctor said lab wouldn't do it (0.00%, n=0)
- Doctor requested and lab didn't do (0.00%, n=0)

Thyroglobulin Antibodies (TgAb)

- Wasn't given a reason (28.57%, n=2)
- Not due another test yet (0.00%, n=0)
- No relevant symptoms (14.29%, n=1)
- Offered other tests first (0.00%, n=0)
- Policy of GP surgery/practice (14.29%, n=1)
- Hypothyroidism guidelines (28.57%, n=2)
- Cost (14.29%, n=1)
- Doctor said lab wouldn't do it (0.00%, n=0)
- Doctor requested and lab didn't do (0.00%, n=0)

Reverse T3

- Wasn't given a reason (30.00%, n=3)
- Not due another test yet (0.00%, n=0)
- No relevant symptoms (10.00%, n=1)
- Offered other tests first (10.00%, n=1)
- Policy of GP surgery/practice (10.00%, n=1)
- Hypothyroidism guidelines (10.00%, n=1)
- Cost (10.00%, n=1)
- Doctor said lab wouldn't do it (0.00%, n=0)
- Doctor requested and lab didn't do (20.00%, n=2)

DIO2 gene

- Wasn't given a reason (33.33%, n=2)
- Not due another test yet (0.00%, n=0)
- No relevant symptoms (16.67%, n=1)
- Offered other tests first (0.00%, n=0)
- Policy of GP surgery/practice (16.67%, n=1)
- Hypothyroidism guidelines (16.67%, n=1)
- Cost (16.67%, n=1)
- Doctor said lab wouldn't do it (0.00%, n=0)
- Doctor requested and lab didn't do (0.00%, n=0)

NHS Endocrinologist/Consultant

- TSH
 - Wasn't given a reason (50.00%, n=12)
 - Not due another test yet (12.50%, n=3)
 - No relevant symptoms (8.33%, n=2)
 - Offered other tests first (0.00%, n=0)
 - Policy of GP surgery/practice (4.17%, n=1)
 - Hypothyroidism guidelines (20.83%, n=5)
 - Cost (0.00%, n=0)
 - Doctor said lab wouldn't do it (4.17%, n=1)
 - Doctor requested and lab didn't do (0.00%, n=0)

FT4

- Wasn't given a reason (28.57%, n=10)
- Not due another test yet (5.71%, n=2)
- No relevant symptoms (14.29%, n=5)
- Offered other tests first (0.00%, n=0)
- Policy of GP surgery/practice (2.86%, n=1)
- Hypothyroidism guidelines (28.57%, n=10)
- Cost (0.00%, n=0)
- Doctor said lab wouldn't do it (17.14%, n=6)
- Doctor requested and lab didn't do (2.86%, n=1)

FT3

- Wasn't given a reason (30.88%, n=21)
- Not due another test yet (2.94%, n=2)
- No relevant symptoms (10.29%, n=7)
- Offered other tests first (1.47%, n=1)
- Policy of GP surgery/practice (2.97%, n=2)
- Hypothyroidism guidelines (25.00%, n=17)
- Cost (4.41%, n=3)
- Doctor said lab wouldn't do it (11.76%, n=8)
- Doctor requested and lab didn't do (10.29%, n=7)

Thyroid Peroxidase Antibodies (TPO)

- Wasn't given a reason (50.98%, n=26)
- Not due another test yet (1.96%, n=1)
- No relevant symptoms (3.92%, n=2)
- Offered other tests first (3.92%, =2)
- Policy of GP surgery/practice (3.92%, n=2)
- Hypothyroidism guidelines (25.49%, n=13)
- Cost (1.96%, n=1)
- Doctor said lab wouldn't do it (5.88%, n=3)
- Doctor requested and lab didn't do (1.96%, n=1)

Thyroglobulin Antibodies (TgAb)

- Wasn't given a reason (52.00%, n=26)
- Not due another test yet (2.00%, n=1)
- No relevant symptoms (8.00%, n=4)
- Offered other tests first (0.00%, n=0)
- Policy of GP surgery/practice (2.00%, n=1)
- Hypothyroidism guidelines (24.00%, n=12)
- Cost (2.00%, n=1)
- Doctor said lab wouldn't do it (8.00%, n=4)
- Doctor requested and lab didn't do (2.00%, n=1)

Reverse T3

- Wasn't given a reason (44.30%, n=35)
- Not due another test yet (0.00%, n=0)
- No relevant symptoms (6.33%, n=5)
- Offered other tests first (2.53%, n=2)
- Policy of GP surgery/practice (2.53%, n=2)
- Hypothyroidism guidelines (18.99%, n=15)
- Cost (2.53%, n=2)
- Doctor said lab wouldn't do it (22.78%, n=18)
- Doctor requested and lab didn't do (0.00%, n=0)

- DIO2 gene
 - Wasn't given a reason (54.90%, n=28)
 - Not due another test yet (0.00%, n=0)
 - No relevant symptoms (5.88%, n=3)
 - Offered other tests first (0.00%, n=0)
 - Policy of GP surgery/practice (3.92%, n=2)
 - Hypothyroidism guidelines (19.61%, n=10)
 - Cost (1.96%, n=1)
 - Doctor said lab wouldn't do it (13.73%, n=7)
 - Doctor requested and lab didn't do (0.00%, n=0)

Private Endocrinologist/Consultant

- TSH
 - Wasn't given a reason (0.00%, n=0)
 - Not due another test yet (100.00%, n=1)
 - No relevant symptoms (0.00%, n=0)
 - Offered other tests first (0.00%, n=0)
 - Policy of GP surgery/practice (0.00%, n=0)
 - Hypothyroidism guidelines (0.00%, n=0)
 - Cost (0.00%, n=0)
 - Doctor said lab wouldn't do it (0.00%, n=0)
 - Doctor requested and lab didn't do (0.00%, n=0)

• FT4

- Wasn't given a reason (0.00%, n=0)
- Not due another test yet (0.00%, n=0)
- No relevant symptoms (0.00%, n=0)
- Offered other tests first (40.00%, n=2)
- Policy of GP surgery/practice (0.00%, n=0)
- Hypothyroidism guidelines (40.00%, n=2)
- Cost (0.00%, n=0)
- Doctor said lab wouldn't do it (20.00%, n=1)
- Doctor requested and lab didn't do (0.00%, n=0)

FT3

- Wasn't given a reason (33.33%, n=3)
- Not due another test yet (0.00%, n=0)
- No relevant symptoms (11.11%, n=1)
- Offered other tests first (11.11%, n=1)
- Policy of GP surgery/practice (0.00%, n=0)
- Hypothyroidism guidelines (22.22%, n=2)
- Cost (0.00%, n=0)
- Doctor said lab wouldn't do it (11.11%, n=1)
- Doctor requested and lab didn't do (11.11%, n=1)

- Thyroid Peroxidase Antibodies (TPO)
 - Wasn't given a reason (83.33%, n=5)
 - Not due another test yet (0.00%, n=0)
 - No relevant symptoms (0.00%, n=0)
 - Offered other tests first (0.00%, n=0)
 - Policy of GP surgery/practice (0.00%, n=0)
 - Hypothyroidism guidelines (0.00%, n=0)
 - Cost (0.00%, n=0)
 - Doctor said lab wouldn't do it (0.00%, n=0)
 - Doctor requested and lab didn't do (16.67%, n=1)

Thyroglobulin Antibodies (TgAb)

- Wasn't given a reason (75.00%, n=6)
- Not due another test yet (0.00%, n=0)
- No relevant symptoms (0.00%, n=0)
- Offered other tests first (0.00%, n=0)
- Policy of GP surgery/practice (0.00%, n=0)
- Hypothyroidism guidelines (12.50%, n=1)
- Cost (0.00%, n=0)
- Doctor said lab wouldn't do it (0.00%, n=0)
- Doctor requested and lab didn't do (12.50%, n=1)

Reverse T3

- Wasn't given a reason (66.67%, n=6)
- Not due another test yet (0.00%, n=0)
- No relevant symptoms (0.00%, n=0)
- Offered other tests first (0.00%, n=0)
- Policy of GP surgery/practice (0.00%, n=0)
- Hypothyroidism guidelines (11.11%, n=1)
- Cost (0.00%, n=0)
- Doctor said lab wouldn't do it (0.00%, n=0)
- Doctor requested and lab didn't do (22.22%, n=2)

DIO2 gene

- Wasn't given a reason (66.67%, n=4)
- Not due another test yet (0.00%, n=0)
- No relevant symptoms (0.00%, n=0)
- Offered other tests first (0.00%, n=0)
- Policy of GP surgery/practice (0.00%, n=0)
- Hypothyroidism guidelines (0.00%, n=0)
- Cost (0.00%, n=0)
- Doctor said lab wouldn't do it (16.67%, n=1)
- Doctor requested and lab didn't do (16.67%, n=1)

Other clinician

TSH

- Wasn't given a reason (9.09%, n=1)
- Not due another test yet (27.27%, n=3)
- No relevant symptoms (0.00%, n=0)
- Offered other tests first (18.18%, n=2)
- Policy of GP surgery/practice (9.09%, n=1)
- Hypothyroidism guidelines (9.09%, n=1)
- Cost (0.00%, n=0)
- Doctor said lab wouldn't do it (27.27%, n=3)
- Doctor requested and lab didn't do (0.00%, n=0)

FT4

- Wasn't given a reason (18.18%, n=2)
- Not due another test yet (9.09%, n=1)
- No relevant symptoms (9.09%, n=1)
- Offered other tests first (0.00%, n=0)
- Policy of GP surgery/practice (9.09%, n=1)
- Hypothyroidism guidelines (27.27%, n=3)
- Cost (9.09%, n=1)
- Doctor said lab wouldn't do it (0.00%, n=0)
- Doctor requested and lab didn't do (18.18%, n=2)

FT3

- Wasn't given a reason (10.53%, n=2)
- Not due another test yet (0.00%, n=0)
- No relevant symptoms (0.00%, n=0)
- Offered other tests first (0.00%, n=0)
- Policy of GP surgery/practice (10.53%, n=2)
- Hypothyroidism guidelines (21.05%, n=4)
- Cost (5.26%, n=1)
- Doctor said lab wouldn't do it (10.53%, n=2)
- Doctor requested and lab didn't do (42.11%, n=8)

Thyroid Peroxidase Antibodies (TPO)

- Wasn't given a reason (12.50%, n=1)
- Not due another test yet (12.50%, n=1)
- No relevant symptoms (12.50%, n=1)
- Offered other tests first (0.00%, n=0)
- Policy of GP surgery/practice (0.00%, n=0)
- Hypothyroidism guidelines (25.00%, n=2)
- Cost (12.50%, n=1)
- Doctor said lab wouldn't do it (12.50%, n=1)
- Doctor requested and lab didn't do (12.50%, n=1)

- Thyroglobulin Antibodies (TqAb)
 - Wasn't given a reason (25.00%, n=2)
 - Not due another test yet (12.50%, n=1)
 - No relevant symptoms (12.50%, n=1)
 - Offered other tests first (0.00%, n=0)
 - Policy of GP surgery/practice (0.00%, n=0)
 - Hypothyroidism guidelines (12.50%, n=1)
 - Cost (12.50%, n=1)
 - Doctor said lab wouldn't do it (12.50%, n=1)
 - Doctor requested and lab didn't do (12.50%, n=1)

Reverse T3

- Wasn't given a reason (44.44%, n=4)
- Not due another test yet (0.00%, n=0)
- No relevant symptoms (0.00%, n=0)
- Offered other tests first (0.00%, n=0)
- Policy of GP surgery/practice (0.00%, n=0)
- Hypothyroidism guidelines (11.11%, n=1)
- Cost (0.00%, n=0)
- Doctor said lab wouldn't do it (33.33%, n=3)
- Doctor requested and lab didn't do (11.11%, n=1)

DIO2 gene

- Wasn't given a reason (66.67%, n=4)
- Not due another test yet (0.00%, n=0)
- No relevant symptoms (0.00%, n=0)
- Offered other tests first (0.00%, n=0)
- Policy of GP surgery/practice (0.00%, n=0)
- Hypothyroidism guidelines (0.00%, n=0)
- Cost (16.67%, n=1)
- Doctor said lab wouldn't do it (0.00%, n=0)
- Doctor requested and lab didn't do (16.67%, n=1)

24. Have you visited a PRIVATE GP/Endocrinologist regarding your thyroid health?

- Yes (22.77%, n=979)
- No (77.23%, n=3,320)

25. What is the furthest you have travelled to visit a private GP/Endocrinologist (there and back)?

- Less than 20 miles (31.81%, n=313)
- 20 100 miles (32.72%, n=322)
- 101 500 miles (23.88%, n=235)
- 501 1000 miles (3.46%, n=34)
- 1001 5000 miles (2.95%, n=29)
- More than 5000 miles (1.73%, n=17)
- I don't know (3.46%, n=34)

26. Approximately how much have you spent on visiting private GP's/Endocrinologists for your thyroid health?

- Up to £100
 - Paid from my own funds (70.77%, n=46)
 - Someone else paid for me (9.23%, n=6)
 - Covered by medical insurance (23.08%, n=15)
- £101 £200
 - Paid from my own funds (68.91%, n=82)
 - Someone else paid for me (10.92%, n=13)
 - Covered by medical insurance (25.21%, n=30)
- £201 £300
 - Paid from my own funds (72.03%, n=85)
 - Someone else paid for me (13.56%, n=16)
 - Covered by medical insurance (14.41%, n=17)
- £301 £400
 - Paid from my own funds (78.95%, n=60)
 - Someone else paid for me (1.32%, n=1)
 - Covered by medical insurance (23.68%, n=18)
- £401 £500
 - Paid from my own funds (74.77%, n=80)
 - Someone else paid for me (6.54%, n=7)
 - Covered by medical insurance (19.63%, n=21)
- £501 £1000
 - Paid from my own funds (77.35%, n=140)
 - Someone else paid for me (8.29%, n=15)
 - Covered by medical insurance (17.13%, n=31)
- £1001 £2000
 - Paid from my own funds (71.22%, n=99)
 - Someone else paid for me (7.19%, n=10)
 - Covered by medical insurance (25.90%, n=36)
- £2001 £5000
 - Paid from my own funds (70.71%, n=70)
 - Someone else paid for me (5.05%, n=5)
 - Covered by medical insurance (29.29%, n=29)
- More than £5000
 - Paid from my own funds (65.08%, n=41)
 - Someone else paid for me (7.94%, n=5)
 - Covered by medical insurance (31.75%, n=20)
- I don't know I didn't keep track
 - Paid from my own funds (56.12%, n=55)
 - Someone else paid for me (9.18%, n=9)
 - Covered by medical insurance (44.90%, n=44)

27. Have you arranged your own private thyroid testing?

- Yes (16.49%, n=709)
- No (83.51%, n=3,590)

28. Approximately how much have you spent on private thyroid testing?

- Up to £100 (8.99%, n=64)
- £101 £200 (21.21%, n=151)
- £201 £300 (15.73%, n=112)
- £301 £400 (10.96%, n=78)
- £401 £500 (9.83%, n=70)
- £501 £1000 (10.39%, n=74)
- More than £1000 (8.15%, n=58)
- I don't know it was included in my consultation fee (4.35%, n=31)
- I don't know I didn't keep track (7.16%, n=51)
- Other (please specify) (3.23%, n=23)

29. Did your NHS clinician tell you about the following thyroid medications?

- Levothyroxine (T4)
 - GP (80.90%, n=3,423)
 - Endocrinologist (19.97%, n=845)
 - Thyroid surgeon (4.02%, n=170)
 - Other speciality clinician (2.51%, n=106)
 - I wasn't told about this (10.42%, n=441)
- Liothyronine (T3)
 - GP (2.41%, n=70)
 - Endocrinologist (9.39%, n=273)
 - Thyroid surgeon (0.96%, n=28)
 - Other speciality clinician (2.68%, n=78)
 - I wasn't told about this (85.83%, n=2,496)
- Slow release T3
 - GP (0.44%, n=12)
 - Endocrinologist (0.69%, n=19)
 - Thyroid surgeon (0.18%, n=5)
 - Other speciality clinician (1.13%, n=31)
 - I wasn't told about this (98.21%, n=2,694)
- Natural desiccated thyroid (NDT) (Armour, NatureThroid, WP Thyroid, Erfa)
 - GP (0.84%, n=24)
 - Endocrinologist (2.63%, n=75)
 - Thyroid surgeon (0.46%, n=13)
 - Other speciality clinician (4.34%, n=124)
 - I wasn't told about this (92.75%, n=2,647)

- Special order levothyroxine (lactose free; filler free; liquid)
 - GP (0.91%, n=25)
 - Endocrinologist (0.66%, n=18)
 - Thyroid surgeon (0.15%, n=4)
 - Other speciality clinician (0.84%, n=23)
 - I wasn't told about this (97.89%, n=2,689)

30. Did you ask your NHS clinician to prescribe T3?

- Yes (27.42%, n=1,179)
- No (72.58%, n=3,120)

31. Did your NHS clinician refuse to prescribe T3?

- Yes (72.34%, n=858)
- No (27.66%, n=328)

32. What was the reason for the refusal to prescribe T3?

- Budget constraints
 - NHS GP (92.11%, n=105)
 - NHS Endocrinologist/Consultant (16.67%, n=19)
 - Other NHS clinician (1.75%, n=2)
- Didn't know anything about this medication
 - NHS GP (94.57%, n=209)
 - NHS Endocrinologist/Consultant (8.14%, n=18)
 - Other NHS clinician (3.2%, n=8)
- Not in the British National Formulary
 - NHS GP (87.97%, n=117)
 - NHS Endocrinologist/Consultant (23.31%, n=31)
 - Other NHS clinician (1.50%, n=2)
- Royal College of Physician's Guidance
 - NHS GP (70.87%, n=73)
 - NHS Endocrinologist/Consultant (38.83%, n=40)
 - Other NHS clinician (4.85%, n=5)
- Would like to but not allowed
 - NHS GP (90.09%, n=100)
 - NHS Endocrinologist/Consultant (8.11%, n=9)
 - Other NHS clinician (3.60%, n=4)
- Clinical Commissioning Group policy
 - NHS GP (81.82%, n=45)
 - NHS Endocrinologist/Consultant (25.45%, n=14)
 - Other NHS clinician (5.45%, n=3)

- PCT policy
 - NHS GP (90.74%, n=49)
 - NHS Endocrinologist/Consultant (9.26%, n=5)
 - Other NHS clinician (3.70%, n=2)
- Health Board policy
 - NHS GP (84.00%, n=42)
 - NHS Endocrinologist/Consultant (18.00%, n=9)
 - Other NHS clinician (4.00%, n=2)
- Would not accept recommendation to prescribe from a private clinician
 - NHS GP (92.98%, n=53)
 - NHS Endocrinologist/Consultant (15.79%, n=9)
 - Other NHS clinician (1.75%, n=1)
- Would not give a reason
 - NHS GP (72.73%, n=104)
 - NHS Endocrinologist/Consultant (29.37%, n=42)
 - Other NHS clinician (4.90%, n=7)
- I can't remember the reason
 - NHS GP (87.80%, n=36)
 - NHS Endocrinologist/Consultant (12.20%, n=5)
 - Other NHS clinician (7.32%, n=3)
- No evidence of superiority over levothyroxine
 - NHS GP (74.49%, n=254)
 - NHS Endocrinologist/Consultant (32.55%, n=111)
 - Other NHS clinician (2.93%, n=10)
- Concerns about potential harm to patients
 - NHS GP (64.81%, n=105)
 - NHS Endocrinologist/Consultant (48.15%, n=78)
 - Other NHS clinician (3.09%, n=5)
- Other reason for refusing
 - NHS GP (58.91%, n=76)
 - NHS Endocrinologist/Consultant (40.31%, n=52)
 - Other NHS clinician (8.53%, n=11)
- 33. Did you ask your NHS clinician to prescribe slow release T3?
 - Yes (5.35%, n=230)
 - No (94.65%, n=4,069)
- 34. Did your NHS clinician refuse to prescribe slow release T3?
 - Yes (88.84%, n=207)
 - No (11.16%, n=26)

35. What was the reason for the refusal to prescribe slow release T3?

- Budget constraints
 - NHS GP (100.00%, n=23)
 - NHS Endocrinologist/Consultant (13.04%, n=3)
 - Other NHS clinician (4.35%, n=1)
- Didn't know anything about this medication
 - NHS GP (96.43%, n=54)
 - NHS Endocrinologist/Consultant (5.36%, n=3)
 - Other NHS clinician (3.57%, n=2)
- Not in the British National Formulary
 - NHS GP (87.10%, n=27)
 - NHS Endocrinologist/Consultant (32.26%, n=10)
 - Other NHS clinician (0.00%, n=0)
- Royal College of Physician's Guidance
 - NHS GP (77.78%, n=14)
 - NHS Endocrinologist/Consultant (44.44%, n=8)
 - Other NHS clinician (0.00%, n=0)
- · Not Licenced in the UK
 - NHS GP (81.48%, n=22)
 - NHS Endocrinologist/Consultant (22.22%, n=6)
 - Other NHS clinician (11.11%, n=3)
- · Would like to but not allowed
 - NHS GP (93.55%, n=29)
 - NHS Endocrinologist/Consultant (12.90%, n=4)
 - Other NHS clinician (0.00%, n=0)
- Clinical Commissioning Group policy
 - NHS GP (83.33%, n=10)
 - NHS Endocrinologist/Consultant (25.00%, n=3)
 - Other NHS clinician (0.00%, n=0)
- PCT policy
 - NHS GP (100.00%, n=10)
 - NHS Endocrinologist/Consultant (10.00%, n=1)
 - Other NHS clinician (0.00%, n=0)
- Health Board policy
 - NHS GP (75.00%, n=6)
 - NHS Endocrinologist/Consultant (25.00%, n=2)
 - Other NHS clinician (0.00%, n=0)
- Would not accept recommendation to prescribe from a private clinician
 - NHS GP (90.91%, n=10)
 - NHS Endocrinologist/Consultant (36.36%, n=4)
 - Other NHS clinician (18.18%, n=2)

- Would not give a reason
 - NHS GP (75.68%, n=28)
 - NHS Endocrinologist/Consultant (43.24%, n=16)
 - Other NHS clinician (5.41%, n=2)
- I can't remember the reason
 - NHS GP (87.50%, n=7)
 - NHS Endocrinologist/Consultant (12.50%, n=1)
 - Other NHS clinician (0.00%, n=0)
- No evidence of superiority over levothyroxine
 - NHS GP (84.38%, n=54)
 - NHS Endocrinologist/Consultant (25.00%, n=16)
 - Other NHS clinician (1.56%, n=1)
- Concerns about potential harm to patients
 - NHS GP (66.67%, n=14)
 - NHS Endocrinologist/Consultant (52.38%, n=11)
 - Other NHS clinician (4.76%, n=1)
- Other reason for refusing
 - NHS GP (76.92%, n=20)
 - NHS Endocrinologist/Consultant (34.62%, n=9)
 - Other NHS clinician (3.85%, n=1)

36. Did you ask your NHS clinician to prescribe natural desiccated thyroid (NDT)?

- Yes (23.52 n=1,011)
- No (76.48%, n=3,288)

37. Did your NHS clinician refuse to prescribe natural desiccated thyroid?

- Yes (92.09%, n=931)
- No (7.91%, n=80)

38. What was the reason for the refusal to prescribe natural desiccated thyroid?

- Budget constraints
 - NHS GP (91.92%, n=91)
 - NHS Endocrinologist/Consultant (15.15%, n=15)
 - Other NHS clinician (1.01%, n=1)
- Didn't know anything about this medication
 - NHS GP (95.86%, n=347)
 - NHS Endocrinologist/Consultant (11.33%, n=41)
 - Other NHS clinician (3.31%, n=12)
- Not in the British National Formulary
 - NHS GP (82.70%, n=196)
 - NHS Endocrinologist/Consultant (30.80%, n=73)
 - Other NHS clinician (3.38%, n=8)

- Royal College of Physician's Guidance
 - NHS GP (69.92%, n=86)
 - NHS Endocrinologist/Consultant (51.22%, n=63)
 - Other NHS clinician (3.25%, n=4)
- Not Licenced in the UK
 - NHS GP (81.36%, n=310)
 - NHS Endocrinologist/Consultant (35.43%, n=135)
 - Other NHS clinician (2.62%, n=10)
- Would like to but not allowed
 - NHS GP (81.30%, n=100)
 - NHS Endocrinologist/Consultant (23.58%, n=29)
 - Other NHS clinician (1.63%, n=2)
- Clinical Commissioning Group policy
 - NHS GP (68.97%, n=40)
 - NHS Endocrinologist/Consultant (39.66%, n=23)
 - Other NHS clinician (8.62%, n=5)
- PCT policy
 - NHS GP (81.93%, n=68)
 - NHS Endocrinologist/Consultant (30.12%, n=25)
 - Other NHS clinician (2.41%, n=2)
- Health Board policy
 - NHS GP (71.23%, n=52)
 - NHS Endocrinologist/Consultant (43.84%, n=32)
 - Other NHS clinician (2.74%, n=2)
- Would not accept recommendation to prescribe from a private clinician
 - NHS GP (90.00%, n=63)
 - NHS Endocrinologist/Consultant (20.00%, n=14)
 - Other NHS clinician (7.14%, n=5)
- Would not give a reason
 - NHS GP (74.03%, n=57)
 - NHS Endocrinologist/Consultant (28.57%, n=22)
 - Other NHS clinician (7.79%, n=6)
- I can't remember the reason
 - NHS GP (70.37%, n=19)
 - NHS Endocrinologist/Consultant (29.63%, n=8)
 - Other NHS clinician (3.70%, n=1)
- No evidence of superiority over levothyroxine
 - NHS GP (71.22%, n=240)
 - NHS Endocrinologist/Consultant (42.43%, n=143)
 - Other NHS clinician (2.67%, n=9)

- Concerns about potential harm to patients
 - NHS GP (69.95%, n=142)
 - NHS Endocrinologist/Consultant (49.75%, n=101)
 - Other NHS clinician (2.46%, n=5)
- Other reason for refusing
 - NHS GP (62.14%, n=64)
 - NHS Endocrinologist/Consultant (45.63%, n=47)
 - Other NHS clinician (7.77%, n=8)

39. Did you ask your NHS clinician to prescribe a special order levothyroxine i.e. lactose free?

- Yes (3.58%, n=154)
- No (96.42%, n=4,145)

40. Did your NHS clinician refuse to prescribe a special order levothyroxine i.e. lactose free?

- Yes (60.26%, n=94)
- No (39.74%, n=62)

41. What was the reason for the refusal to prescribe a special order levothyroxine? i.e. lactose free?

- Budget constraints
 - NHS GP (100.00%, n=35)
 - NHS Endocrinologist/Consultant (0.00%, n=0)
 - Other NHS clinician (0.00%, n=0)
- Didn't know anything about this medication
 - NHS GP (96.43%, n=27)
 - NHS Endocrinologist/Consultant (10.71%, n=3)
 - Other NHS clinician (7.14%, n=2)
- Not in the British National Formulary
 - NHS GP (100.00%, n=7)
 - NHS Endocrinologist/Consultant (0.00%, n=0)
 - Other NHS clinician (0.00%, n=0)
- Not Licenced in the UK
 - NHS GP (100.00%, n=9)
 - NHS Endocrinologist/Consultant (22.22%, n=2)
 - Other NHS clinician (11.11%, n=1)
- Would like to but not allowed
 - NHS GP (100.00%, n=8)
 - NHS Endocrinologist/Consultant (0.00%, n=0)
 - Other NHS clinician (0.00%, n=0)

- · Clinical Commissioning Group policy
 - NHS GP (100.00%, n=3)
 - NHS Endocrinologist/Consultant (33.33%, n=1)
 - Other NHS clinician (0.00%, n=0)
- PCT policy
 - NHS GP (75.00%, n=3)
 - NHS Endocrinologist/Consultant (25.00%, n=1)
 - Other NHS clinician (0.00%, n=0)
- Health Board policy
 - NHS GP (100.00%, n=1)
 - NHS Endocrinologist/Consultant (0.00%, n=0)
 - Other NHS clinician (0.00%, n=0)
- Would not accept recommendation to prescribe from a private clinician
 - NHS GP (100.00%, n=5)
 - NHS Endocrinologist/Consultant (0.00%, n=0)
 - Other NHS clinician (0.00%, n=0)
- Would not give a reason
 - NHS GP (88.89%, n=8)
 - NHS Endocrinologist/Consultant (11.11%, n=1)
 - Other NHS clinician (0.00%, n=0)
- I can't remember the reason
 - NHS GP (100.00%, n=2)
 - NHS Endocrinologist/Consultant (0.00%, n=0)
 - Other NHS clinician (0.00%, n=0)
- No evidence of superiority over levothyroxine
 - NHS GP (93.75%, n=15)
 - NHS Endocrinologist/Consultant (12.50%, n=2)
 - Other NHS clinician (6.25%, n=1)
- No evidence of my need for this medication
 - NHS GP (85.71%, n=18)
 - NHS Endocrinologist/Consultant (14.29%, n=3)
 - Other NHS clinician (9.52%, n=2)
- Other reason for refusing
 - NHS GP (78.57%, n=11)
 - NHS Endocrinologist/Consultant (21.42%, n=3)
 - Other NHS clinician (0.00%, n=0)

42. Are you CURRENTLY taking medication for your hypothyroidism?

- Yes (93.16%, n=4,005)
- No (6.84%, n=294)

43. What thyroid medications are you currently taking?

- Levothyroxine (T4)
 - Prescribed by my NHS GP (NHS prescription) (93.45%, n=3,155)
 - Prescribed by my NHS GP (private prescription) (0.53%, n=18)
 - Prescribed by my private GP (0.95%, n=32)
 - Prescribed by my NHS endocrinologist/consultant (7.94%, n=268)
 - Prescribed by my private endocrinologist/consultant (1.63%, n=55)
 - Purchase it myself online (without an NHS prescription) (0.27%, n=9)
 - Obtaining it some other way (0.21%, n=7)

• Liothyronine (T3)

- Prescribed by my NHS GP (NHS prescription) (35.63%, n=181)
- Prescribed by my NHS GP (private prescription) (2.56%, n=13)
- Prescribed by my private GP (4.33%, n=22)
- Prescribed by my NHS endocrinologist/consultant (31.30%, n=159)
- Prescribed by my private endocrinologist/consultant (9.25%, n=47)
- Purchase it myself online (without an NHS prescription) (23.62%, n=120)
- Obtaining it some other way (4.92%, n=25)

Slow release T3

- Prescribed by my NHS GP (NHS prescription) (6.06%, n=2)
- Prescribed by my NHS GP (private prescription) (15.15%, n=5)
- Prescribed by my private GP (6.06%, n=2)
- Prescribed by my NHS endocrinologist/consultant (12.12%, n=4)
- Prescribed by my private endocrinologist/consultant (18.18%, n=6)
- Purchase it myself online (without an NHS prescription) (30.30%, n=10)
- Obtaining it some other way (12.12%, n=4)

Natural desiccated thyroid (NDT)

- Prescribed by my NHS GP (NHS prescription) (9.69%, n=58)
- Prescribed by my NHS GP (private prescription) (3.81%, n=22)
- Prescribed by my private GP (7.44%, n=43)
- Prescribed by my NHS endocrinologist/consultant (4.84%, n=28)
- Prescribed by my private endocrinologist/consultant (9.86%, n=57)
- Purchase it myself online (without an NHS prescription) (61.94%, n=358)
- Obtaining it some other way (6.75%, n=39)
- Special order levothyroxine i.e.lactose free, filler free etc.
 - Prescribed by my NHS GP (NHS prescription) (31.51%, n=23)
 - Prescribed by my NHS GP (private prescription) (15.07%, n=11)
 - Prescribed by my private GP (5.48%, n=4)
 - Prescribed by my NHS endocrinologist/consultant (17.81%, n=13)
 - Prescribed by my private endocrinologist/consultant (17.81%, n=13)
 - Purchase it myself online (without an NHS prescription) (10.96%, n=8)
 - Obtaining it some other way (8.22%, n=6)

- Glandulars/thyroid extract
 - Prescribed by my NHS GP (NHS prescription) (3.45%, n=3)
 - Prescribed by my NHS GP (private prescription) (4.60%, n=4)
 - Prescribed by my private GP (9.20%, n=8)
 - Prescribed by my NHS endocrinologist/consultant (1.15%, n=1)
 - Prescribed by my private endocrinologist/consultant (9.20%, n=8)
 - Purchase it myself online (without an NHS prescription) (65.52%, n=57)
 - Obtaining it some other way (9.20%, n=8)

44. Have your hypothyroid symptoms IMPROVED since taking your thyroid medication?

- Yes (61.25%, n=2,453)
- No (38.75%, n=1,552)

45. Which thyroid medication improved your hypothyroid symptoms?

- Levothyroxine (T4) only
 - Totally (7.15%, n=142)
 - Significantly (40.53%, n=805)
 - Slightly (39.88%, n=792)
 - Not at all (6.04%, n=120)
 - Briefly (6.39%, n=127)
- Liothyronine (T3) only
 - Totally (17.81%, n=44)
 - Significantly (55.47%, n=137)
 - Slightly (16.19%, n=40)
 - Not at all (6.07%, n=15)
 - Briefly (4.45%, n=11)
- Combination of levothyroxine (T4) and liothyronine (T3)
 - Totally (9.84%, n=30)
 - Significantly (51.15%, n=156)
 - Slightly (23.93%, n=73)
 - Not at all (7.54%, n=23)
 - Briefly (7.54%, n=23)
- Slow release T3 only
 - Totally (31.58%, n=6)
 - Significantly (26.32%, n=5)
 - Slightly (15.79%, n=3)
 - Not at all (21.05%, n=4)
 - Briefly (5.26%, n=1)
- Combination of levothyroxine (T4) and slow release T3
 - Totally (4.17%, n=1)
 - Significantly (33.33%, n=8)
 - Slightly (16.67%, n=4)
 - Not at all (29.17%, n=7)
 - Briefly (16.67%, n=4)

- Natural desiccated thyroid (NDT) only
 - Totally (28.99%, n=138)
 - Significantly (56.72%, n=270)
 - Slightly (10.50%, n=50)
 - Not at all (2.31%, n=11)
 - Briefly (1.47%, n=7)
- Combination of natural desiccated thyroid (NDT) and levothyroxine (T4)
 - Totally (11.11%, n=6)
 - Significantly (50.00%, n=27)
 - Slightly (18.52%, n=10)
 - Not at all (12.96%, n=7)
 - Briefly (7.41%, n=4)
- Combination of natural desiccated thyroid (NDT) and liothyronine (T3)
 - Totally (16.05%, n=13)
 - Significantly (60.49%, n=49)
 - Slightly (12.35%, n=10)
 - Not at all (6.17%, n=5)
 - Briefly (4.94%, n=4)
- Combination of natural desiccated thyroid (NDT) and levothyroxine (T4) and liothyronine (T3)
 - Totally (27.59%, n=8)
 - Significantly (34.48%, n=10)
 - Slightly (6.90%, n=2)
 - Not at all (20.69%, n=6)
 - Briefly (10.34%, n=3)
- Special order levothyroxine i.e. lactose free, filler free etc.
 - Totally (12.12%, n=4)
 - Significantly (48.48%, n=16)
 - Slightly (24.24%, n=8)
 - Not at all (15.15%, n=5)
 - Briefly (0.00%, n=0)
- Glandulars/thyroid extract
 - Totally (7.14%, n=5)
 - Significantly (47.14%, n=33)
 - Slightly (30.00%, n=21)
 - Not at all (10.00%, n=7)
 - Briefly (5.71%, n=4)
- Other thyroid medication/combination
 - Totally (31.58%, n=12)
 - Significantly (50.00%, n=19)
 - Slightly (5.26%, n=2)
 - Not at all (7.89%, n=3)
 - Briefly (5.26%, n=2)

46. How has this improvement affected the following aspects of your life? Please answer each section. Please rate: 1 = No effect and 10 = Restored completely to normal

- Personal life
 - 1 (2.77%, n=68)
 - 2 (3.87%, n=95)
 - 3 (7.13%, n=175)
 - 4 (8.80%, n=216)
 - 5 (18.09%, n=444)
 - 6 (11.77%, n=289)
 - 7 (15.80%, n=388)
 - 8 (16.74%, n=411)
 - 9 (7.94%, n=195)
 - 10 (7.09%, n=174)

Social life

- 1 (4.28%, n=105)
- 2 (5.58%, n=137)
- 3 (8.59%, n=211)
- 4 (9.41%, n=231)
- 5 (16.74%, n=411)
- 6 (11.73%, n=288)
- 7 (15.40%, n=378)
- 8 (14.58%, n=358)
- 9 (7.17%, n=176)
- 10 (6.52%, n=160)

Working life

- 1 (9.69%, n=238)
- 2 (4.52%, n=111)
- 3 (7.49%, n=184)
- 4 (8.11%, n=199)
- 5 (16.42%, n=403)
- 6 (11.93%, n=293)
- 7 (13.40%, n=329)
- 8 (13.77%, n=338)
- 9 (7.45%, n=183)
- 10 (7.09%, n=177)

47. Since taking thyroid medication, has the amount of OTHER (non-thyroid) prescription medications you are on DECREASED?

- I was never on any non-thyroid prescription medication (44.40%, n=1,780)
- Yes, my non thyroid prescription medications decreased (13.90%, n=555)
- No, my non thyroid prescription medications stayed the same (23.10%, n=924)
- No, my non thyroid prescription medications increased (18.60%, n=746)

48. By how many have your non-thyroid prescription medications decreased?

I was on:

- More than 10 non thyroid prescription meds (2.33%, n=13)
- 10 non thyroid prescription meds (1.79%, n=10)
- 9 non thyroid prescription meds (0.54%, n=3)
- 8 non thyroid prescription meds (1.43%, n=8)
- 7 non thyroid prescription meds (1.43%, n=8)
- 6 non thyroid prescription meds (3.76%, n=21)
- 5 non thyroid prescription meds (6.62%, n=37)
- 4 non thyroid prescription meds (8.94%, n=50)
- 3 non thyroid prescription meds (15.74%, n=88)
- 2 non thyroid prescription meds (25.22%, n=141)
- 1 non thyroid prescription meds (32.20%, n=180)

I am now on:

- 0 non thyroid prescription meds (48.84%, n=273)
- 1 non thyroid prescription meds (31.31%, n=175)
- 2 non thyroid prescription meds (8.59%, n=48)
- 3 non thyroid prescription meds (5.19%, n=29)
- 4 non thyroid prescription meds (2.33%, n=13)
- 5 non thyroid prescription meds (1.25%, n=7)
- 6 non thyroid prescription meds (1.07%, n=6)
- 7 non thyroid prescription meds (0.36%, n=2)
- 8 non thyroid prescription meds (0.18%, n=1)
- 9 non thyroid prescription meds (0.00%, n=0)
- 10 non thyroid prescription meds (0.89%, n=5)

49. Have you PREVIOUSLY been prescribed a thyroid medication that has NOW been refused?

- Yes, even though it was improving my symptoms (4.60%, n=196)
- Yes, although it wasn't really helping anyway (0.60%, n=25)
- No (94.90%, n=4,078)

50. What thyroid medications were you previously prescribed and have now been refused? Please answer who, why and when for each medication you have been refused.

Who Refused:

- Liothyronine (T3)
 - GP (71.88%, n=69)
 - Endocrinologist/Consultant (27.08%, n=26)
 - Other (1.04%, n=1)
- Natural desiccated thyroid (NDT)
 - GP (74.16%, n=66)
 - Endocrinologist/Consultant (20.22%, n=18)
 - Other (5.62%, n=5)

- Special order levothyroxine
 - GP (75.00%, n=18)
 - Endocrinologist/Consultant (12.50%, n=3)
 - Other (12.50%, n=3)
- Slow Release T3
 - GP (61.54%, n=8)
 - Endocrinologist/Consultant (7.69%, n=1)
 - Other (30.77%, n=4)
- Other thyroid Medication
 - GP (79.03%, n=49)
 - Endocrinologist/Consultant (11.29%, n=7)
 - Other (9.68%, n=6)

Why was it refused:

- Liothyronine (T3)
 - Cost (22.34%, n=21)
 - Change of doctor (17.02%, n=16)
 - PCT refused (0.00%, n=0)
 - Health Board refused (1.06%, n=1)
 - CCG refused (6.38%, n=6)
 - New surgery policy (3.19%, n=3)
 - Heath partner said no (7.45%, n=7)
 - Don't know (42.55%, n=40)
- Natural desiccated thyroid (NDT)
 - Cost (10.47%, n=9)
 - Change of doctor (15.12%, n=13)
 - PCT refused (11.63%, n=10)
 - Health Board refused (3.49%, n=3)
 - CCG refused (4.65%, n=4)
 - New surgery policy (5.81%, n=5)
 - Heath partner said no (11.63%, n=10)
 - Don't know (37.21%, n=32)
- Special order levothyroxine
 - Cost (29.17%, n=7)
 - Change of doctor (4.17%, n=1)
 - PCT refused (4.17%, n=1)
 - Health Board refused (0.00%, n=0)
 - CCG refused (4.17%, n=1)
 - New surgery policy (12.50%, n=3)
 - Heath partner said no (4.17%, n=1)
 - Don't know (41.67%, n=10)

- Slow Release T3
 - Cost (33.33%, n=4)
 - Change of doctor (8.33%, n=1)
 - PCT refused (0.00%, n=0)
 - Health Board refused (8.33%, n=1)
 - CCG refused (0.00%, n=0)
 - New surgery policy (8.33%, n=1)
 - Heath partner said no (8.33%, n=1)
 - Don't know (33.33%, n=4)
- Other thyroid Medication
 - Cost (13.33%, n=8)
 - Change of doctor (16.67%, n=10)
 - PCT refused (1.67%, n=1)
 - Health Board refused (0.00%, n=0)
 - CCG refused (3.33%, n=2)
 - New surgery policy (5.00%, n=3)
 - Heath partner said no (10.00%, n=6)
 - Don't know (50.00%, n=30)

When was it refused:

- Liothyronine (T3)
 - Within the last three months (21.88%, n=21)
 - Three to six months ago (10.42%, n=10)
 - Six months to a year ago (12.50%, n=12)
 - Over a year ago (46.88%, n=45)
 - Can't remember (8.33%, n=8)
- Natural desiccated thyroid (NDT)
 - Within the last three months (15.12%, n=13)
 - Three to six months ago (11.63%, n=10)
 - Six months to a year ago (6.98%, n=6)
 - Over a year ago (60.47%, n=52)
 - Can't remember (5.81%, n=5)
- Special order levothyroxine
 - Within the last three months (26.09%, n=6)
 - Three to six months ago (4.35%, n=1)
 - Six months to a year ago (13.04%, n=3)
 - Over a year ago (47.83%, n=11)
 - Can't remember (8.70%, n=2)
- Slow Release T3
 - Within the last three months (7.69%, n=1)
 - Three to six months ago (0.00%, n=0)
 - Six months to a year ago (0.00%, n=0)
 - Over a year ago (61.54%, n=8)
 - Can't remember (30.77%, n=4)

- Other thyroid Medication
 - Within the last three months (20.00%, n=12)
 - Three to six months ago (11.67%, n=7)
 - Six months to a year ago (10.00%, n=6)
 - Over a year ago (48.33%, n=29)
 - Can't remember (10.00%, n=6)

51. If you were refused T3 or natural desiccated thyroid by your Clinical Commissioning Group (CCG)/Health Board, please state below the name of the organisation

- I wasn't refused by my Clinical Commissioning Group/Health Board (70.27%, n=156)
- I was refused by Clinical Commissioning Group/Health Board below: (29.73%, n=66)

52. If your NHS clinician is prescribing your thyroid medications, have you had any of the following problems with supply?

- Levothyroxine (T4)
 - I've never had a problem with supply (77.23%, n=3,039)
 - Manufacturer recall (1.02%, n=40)
 - Manufacturer licence withdrawal (0.66%, n=26)
 - Discontinued by manufacturer (1.45%, n=57)
 - Informed by pharmacy that no longer available (1.45%, n=57)
 - Problem with manufacture (1.98%, n=78)
 - Shortage of supply (2.74%, n=108)
 - Problems getting same brand (11.92%, n=469)
 - I don't know the reason (1.40%, n=55)
 - Not being prescribed on NHS (7.88%, n=310)
- Liothyronine (T3)
 - I've never had a problem with supply (20.02%, n=207)
 - Manufacturer recall (1.35%, n=14)
 - Manufacturer licence withdrawal (1.16%, n=12)
 - Discontinued by manufacturer (0.97%, n=10)
 - Informed by pharmacy that no longer available (2.03%, n=21)
 - Problem with manufacture (5.51%, n=57)
 - Shortage of supply (14.51%, n=150)
 - Problems getting same brand (2.90%, n=30)
 - I don't know the reason (4.55%, n=47)
 - Not being prescribed on NHS (56.19%, n=581)
- Natural desiccated thyroid (NDT)
 - I've never had a problem with supply (8.77%, n=84)
 - Manufacturer recall (0.42%, n=4)
 - Manufacturer licence withdrawal (1.04%, n=10)
 - Discontinued by manufacturer (1.36%, n=13)
 - Informed by pharmacy that no longer available (1.77%, n=17)
 - Problem with manufacture (1.77%, n=17)
 - Shortage of supply (3.97%, n=38)
 - Problems getting same brand (1.15%, n=11)
 - I don't know the reason (3.76%, n=36)
 - Not being prescribed on NHS (81.32%, n=779)

- Special order Levothyroxine
 - I've never had a problem with supply (5.23%, n=32)
 - Manufacturer recall (0.16%, n=1)
 - Manufacturer licence withdrawal (1.14%, n=7)
 - Discontinued by manufacturer (0.98%, n=6)
 - Informed by pharmacy that no longer available (1.31%, n=8)
 - Problem with manufacture (1.63%, n=10)
 - Shortage of supply (1.47%, n=9)
 - Problems getting same brand (2.29%, n=14)
 - I don't know the reason (5.72%, n=35)
 - Not being prescribed on NHS (83.17%, n=509)

53. Are you purchasing or have you ever purchased some or all of your own thyroid medication WITHOUT an NHS or private prescription?

- Yes (24.80%, n=1,066)
- No (75.20%, n=3,233)

54. Approximately how much per month are you or were you spending on your THYROID medication?

- Levothyroxine (T4)
 - Up to £10 (45.11%, n=60)
 - £11 £20 (26.32%, n=35)
 - £21 £30 (10.53%, n=14)
 - £31 £40 (7.52%, n=10)
 - £41 £50 (3.76%, n=5)
 - £51 £100 (4.51%, n=6)
 - More than £100 (2.26%, n=3)
- Liothyronine (T3)
 - Up to £10 (26.26%, n=73)
 - £11 £20 (26.98%, n=75)
 - £21 £30 (13.67%, n=38)
 - £31 £40 (14.75%, n=41)
 - £41 £50 (6.83%, n=19)
 - £51 £100 (5.40%, n=15)
 - More than £100 (6.12%, n=17)
- Natural desiccated thyroid (NDT)
 - Up to £10 (24.21%, n=161)
 - £11 £20 (14.74%, n=98)
 - £21 £30 (18.95%, n=126)
 - £31 £40 (16.24%, n=108)
 - £41 £50 (12.33%, n=82)
 - £51 £100 (9.77%, n=65)
 - More than £100 (3.76%, n=25)

- Other thyroid medication
 - Up to £10 (19.27%, n=37)
 - £11 £20 (18.75%. n=36)
 - £21 £30 (20.83%, n=40)
 - £31 £40 (12.50%, n=24)
 - £41 £50 (9.90%, n=19)
 - £51 £100 (11.98%, n=23)
 - More than £100 (6.77%, n=13)

55. Does your NHS clinician know (or has ever known) that you are self-treating?

- NHS GP
 - Yes (88.29%, n=309)
 - Yes and he is monitoring me (76.43%, n=120)
 - No (94.41%, n=659)
- NHS Endocrinologist/Consultant
 - Yes (39.71%, n=139)
 - Yes and he is monitoring me (36.94%, n=58)
 - No (39.26%, n=274)

56. Were you involved in a discussion around treatment options (shared decision making) with your NHS clinician?

- Yes, with my NHS GP (11.09%, n=634)
- Yes, with my NHS Endocrinologist/Consultant (6.70%, n=383)
- No, my NHS GP was not open to discussion (31.47%, n=1,799)
- No, my NHS Endocrinologist/Consultant was not open to discussion (10.95%, n=626)
- I didn't discuss this with my NHS GP (22.70%, n=1,298)
- I didn't discuss this with my NHS Endocrinologist/Consultant (5.60%, n=320)
- Other (please specify) (11.49%, n=657)

57. How would you rate your NHS GP's knowledge of the following? Please choose an option from each.

- Hypothyroidism
 - Poor (52.57%, n=2,260)
 - Good (26.29%, n-1,130)
 - Very Good (5.68%, n=244)
 - Didn't discuss this at all (15.47%, n=665)
- Testing options
 - Poor (48.85%, n=2,100)
 - Good (18.42%, n=792)
 - Very Good (4.51%, n=194)
 - Didn't discuss this at all (28.22%, n=1,213)

- Liothyronine (T3)
 - Poor (36.71%, n=1,578)
 - Good (4.14%, n=178)
 - Very Good (0.70%, n=30)
 - Didn't discuss this at all (58.46%, n=2,513)
- Natural desiccated thyroid (NDT)
 - Poor (36.54%, n=1,571)
 - Good (1.61%, n=69)
 - Very Good (0.44%, n=19)
 - Didn't discuss this at all (61.41%, n=2,640)

58. Do you feel your NHS GP is confined by any of the following? Please answer all that apply.

- No, I don't feel my GP is confined by any of the below (17.54%, n=754)
- Budget (48.38%, n=2,080)
- Time (42.45%, n=1,825)
- Guidelines (56.20%, n=2,416)
- Other (please specify) (20.70%, n=890)

59. Were you given any information about thyroid disease by your NHS clinician?

- Verbal information on my hypothyroidism
 - NHS GP (81.64%, n=1,387)
 - NHS Endocrinologist/Consultant (37.49%, n=637)
- Given an NHS leaflet about hypothyroidism
 - NHS GP (73.92%, n=360)
 - NHS Endocrinologist/Consultant (30.80%, n=150)
- Given verbal or printed information about Thyroid UK
 - NHS GP (63.48%, n=113)
 - NHS Endocrinologist/Consultant (42.13%, n=75)
- Given verbal or printed information about another support group
 - NHS GP (35.38%, n=23)
 - NHS Endocrinologist/Consultant (66.15%, n=43)
- Was advised to visit NHS Choices
 - NHS GP (77.78%, n=63)
 - NHS Endocrinologist/Consultant (27.16%, n=22)
- Was advised not to go looking on the internet for information
 - NHS GP (80.07%, n=474)
 - NHS Endocrinologist/Consultant (40.54%, n=240)
- I wasn't given any information about my hypothyroidism
 - NHS GP (96.71%, n=2,348)
 - NHS Endocrinologist/Consultant (27.10%, n=658)

- Other
 - NHS GP (81.55%, n=137)
 - NHS Endocrinologist/Consultant (37.50%, n=63)

60. Did your NHS clinician treat you with dignity and respect?

- Yes
 - NHS GP (88.12%, n=2,321)
 - NHS Endocrinologist (26.39%, n=695)
 - Other NHS clinician (6.68%, n=178)
- No
 - NHS GP (58.98%, n=581)
 - NHS Endocrinologist (53.20%, n=524)
 - Other NHS clinician (11.37%, n=112)
- Sometimes
 - NHS GP (86.98%, n=1,363)
 - NHS Endocrinologist (23.74%, n=372)
 - Other NHS clinician (4.53%, n=71)

61. Did you ask your NHS GP for a referral to an NHS endocrinologist and were refused?

- I didn't ask for a referral (53.40%, n=2,296)
- I asked and was refused (13.40%, n=575)
- I asked and I got my referral (29.80%, n=1,282)
- Other (please specify) (3.40%, n=146)

62. What medications have you been prescribed for your symptoms and how much are they improving your symptoms? Please rate: 1 = Not at all and 10 = completely improving my symptoms

- I haven't been prescribed anything for my symptoms
 - 1 (83.02%, n=176)
 - 2 (2.36%, n=5)
 - 3 (2.36%, n=5)
 - 4 (1.42%, n=3)
 - 5 (3.30%, n=7)
 - 6 (1.42%, n=3)
 - 7 (0.94%, n=2)
 - 8 (0.47%, n=1)
 - 9 (0.47%, n=1)
 - 10 (4.25%, n=9)

- Antidepressants
 - 1 (57.67%, n=109)
 - 2 (10.58%, n=20)
 - 3 (6.88%, n=13)
 - 4 (7.94%, n=15)
 - 5 (10.58%, n=20)
 - 6 (2.65%, n=5)
 - 7 (1.59%, n=3)
 - 8 (1.06%, n=2)
 - 9 (0.00%, n=0)
 - 10 (1.06%, n=2)
- Proton pump inhibitors (to reduce stomach acid)
 - 1 (72.86%, n=102)
 - 2 (2.86%, n=4)
 - 3 (5.00%, n=7)
 - 4 (5.71%, n=8)
 - 5 (4.29%, n=6)
 - 6 (2.14%, n=3)
 - 7 (2.14%, n=3)
 - 8 (2.14%, n=3)
 - 9 (0.71%, n=1)
 - 10 (2.14%, n=3)
- Painkillers
 - 1 (55.81%, n=96)
 - 2 (7.56%, n=13)
 - 3 (13.37%, n=23)
 - 4 (4.65%, n=8)
 - 5 (9.88%, n=17)
 - 6 (3.49%, n=6)
 - 7 (1.16%, n=2)
 - 8 (1.16%, n=2)
 - 9 (0.58%, n=1)
 - 10 (2.33%, n=4)
- Statins (to lower cholesterol)
 - 1 (87.72%, n=100)
 - 2 (2.63%, n=3)
 - 3 (1.75%, n=2)
 - 4 (1.75%, n=2)
 - 5 (2.63%, n=3)
 - 6 (0.00%, n=0)
 - 7 (0.88%, n=1)
 - 8 (0.88%, n=1)
 - 9 (0.88%, n=1)
 - 10 (0.88%, n=1)

- HRT (for menopause)
 - 1 (85.12%, n=103)
 - 2 (4.13%, n=5)
 - 3 (0.00%, n=0)
 - 4 (0.83%, n=1)
 - 5 (1.65%, n=2)
 - 6 (0.83%, n=1)
 - 7 (3.31%, n=4)
 - 8 (3.31%, n=4)
 - 9 (0.00%, n=0)
 - 10 (0.83%, n=1)
- Beta blockers (to reduce heart rate)
 - 1 (76.92%, n=100)
 - 2 (2.31%, n=3)
 - 3 (6.15%, n=8)
 - 4 (4.62%, n=6)
 - 5 (3.08%, n=4)
 - 6 (1.54%, n=2)
 - 7 (0.77%, n=1)
 - 8 (3.85%, n=5)
 - 9 (0.00%, n=0)
 - 10 (0.77%, n=1)
- Tranquilisers (for anxiety)
 - 1 (85.12%, n=103)
 - 2 (2.48%, n=3)
 - 3 (4.13%, n=5)
 - 4 (0.83%, n=1)
 - 5 (4.13%, n=5)
 - 6 (1.65%, n=2)
 - 7 (0.00%, n=0)
 - 8 (0.00%, n=0)
 - 9 (0.83%, n=1)
 - 10 (0.83%, n=1)
- Medications for psychosis
 - 1 (93.64%, n=103)
 - 2 (1.82%, n=2)
 - 3 (1.82%, n=2)
 - 4 (0.00%, n=0)
 - 5 (0.91%, n=1)
 - 6 (0.00%, n=0)
 - 7 (0.00%, n=0)
 - 8 (0.91%, n=1)
 - 9 (0.91%, n=1)
 - 10 (0.00%, n=0)

- · Medications for stabilizing mood
 - 1 (86.96%, n=100)
 - 2 (4.35%, n=5)
 - 3 (2.61%, n=3)
 - 4 (1.74%, n=2)
 - 5 (2.61%, n=3)
 - 6 (0.00%, n=0)
 - 7 (0.87%, n=1)
 - 8 (0.00%, n=0)
 - 9 (0.00%, n=0)
 - 10 (0.87%, n=1)
- · Medications for high blood pressure
 - 1 (76.61%, n=95)
 - 2 (2.42%, n=3)
 - 3 (2.42%, n=3)
 - 4 (1.61%, n=2)
 - 5 (3.23%, n=4)
 - 6 (1.61%, n=2)
 - 7 (4.84%, n=6)
 - 8 (4.03%, n=5)
 - 9 (1.61%, n=2)
 - 10 (1.61%, n=2)
- Nifedipine (for Raynaud's phenomenon)
 - 1 (97.06%, n=99)
 - 2 (1.96%, n=2)
 - 3 (0.00%, n=0)
 - 4 (0.98%, n=1)
 - 5 (0.00%, n=0)
 - 6 (0.00%, n=0)
 - 7 (0.00%, n=0)
 - 8 (0.00%, n=0)9 (0.00%, n=0)
 - 10 (0.00%, n=0)
- Sleeping tablets
 - 1 (74.81%, n=98)
 - 2 (3.05%, n=4)
 - 3 (5.34%, n=7)
 - 4 (3.82%, n=5)
 - 5 (7.63%, n=10)
 - 6 (0.00%, n=0)
 - 7 (1.53%, n=2)
 - 8 (1.53%, n=2)
 - 9 (0.76%, n=1)
 - 10 (1.53%, n=2)

- Steroids tablets, creams or injections (for arthritis/joint pain etc)
 - 1 (73.60%, n=92)
 - 2 (4.80%, n=6)
 - 3 (4.00%, n=5)
 - 4 (1.60%, n=2)
 - 5 (4.00%, n=5)
 - 6 (4.80%, n=6)
 - 7 (0.80%, n=1)
 - 8 (0.80%, n=1)
 - 9 (0.00%, n=0)
 - 10 (5.60%, n=7)

Anticonvulsants

- 1 (93.40%, n=99)
- 2 (1.89%, n=2)
- 3 (1.89%, n=2)
- 4 (0.00%, n=0)
- 5 (0.00%, n=0)
- 6 (0.94%, n=1)
- 7 (0.00%, n=0)
- 8 (0.00%, n=0)
- 9 (0.00%, n=0)
- 10 (1.89%, n=2)

Laxatives

- 1 (71.53%, n=98)
- 2 (8.03%, n=11)
- 3 (3.65%, n=5)
- 4 (2.19%, n=3)
- 5 (7.30%, n=10)
- 6 (2.19%, n=3)
- 7 (1.46%, n=2)
- 8 (1.46%, n=2)
- 9 (0.73%, n=1)
- 10 (1.46%, n=2)

Dry skin treatments

- 1 (73.13%, n=98)
- 2 (3.73%, n=5)
- 3 (8.96%, n=12)
- 4 (5.22%, n=7)
- 5 (2.24%, n=3)
- 6 (1.49%, n=2)
- 7 (1.49%, n=2)
- 8 (0.00%, n=0)
- 9 (0.00%, n=0)
- 10 (3.73%, n=5)

Asthma inhaler

- 1 (56.92%, n=74)
- 2 (6.92%, n=9)
- 3 (4.62%, n=6)
- 4 (5.38%, n=7)
- 5 (11.54%, n=15)
- 6 (1.54%, n=2)
- 7 (2.31%, n=3)
- 8 (5.38%, n=7)
- 9 (0.77%, n=1)
- 10 (4.62%, n=8)

Antihistamines

- 1 (66.92%, n=87)
- 2 (2.31%, n=3)
- 3 (6.15%, n=8)
- 4 (6.92%, n=9)
- 5 (11.54%, n=15)
- 6 (2.31%, n=3)
- 7 (0.00%, n=0)
- 8 (1.54%, n=2)
- 9 (0.77%, n=1)
- 10 (1.54%, n=2)

Medications for dry eyes

- 1 (64.23%, n=88)
- 2 (5.84%, n=8)
- 3 (8.03%, n=11)
- 4 (5.84%, n=8)
- 5 (4.38%, n=6)
- 6 (2.19%, n=3)
- 7 (2.19%, n=3)
- 8 (4.38%, n=6)
- 9 (2.19%, n=3)
- 10 (0.73%, n=1)

Other medication(s)

- 1 (60.00%, n=87)
- 2 (2.76%, n=4)
- 3 (5.52%, n=8)
- 4 (3.45%, n=5)
- 5 (7.59%, n=11)
- 6 (6.21%, n=9)
- 7 (2.76%, n=4)
- 8 (2.07%, n=3)
- 9 (1.38%, n=2)
- 10 (8.28%, n=12)

63. On average how often do you visit your GP with symptoms?

- Once a week (0.00%, n=0)
- More than once a week (0.63%, n=2)
- Once a fortnight (4.39%, n=14)
- Once a month (21.32%, n=68)
- More than once a month (4.70%, n=15)
- Once every few months (37.62%, n=120)
- Less than once a year (19.44%, n=62)
- Other (please specify) (11.91%, n=38)

64. Have you been diagnosed with any health conditions?

- Yes (72.10%, n=230)
- No (27.90%, n=89)

65. Do you have any other comments about your thyroid diagnosis and treatment?

See Appendix F

66. Are you a paying member of Thyroid UK?

- Yes (13.86%, n=596)
- No (86.14%, n=3,703)