

Appendix D – Survey Questions

1. Age
2. Gender
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	Hair changes
Appetite changes	Voice changes
Weight gain	Poor motor skills
Aches and pains	Poor co-ordination
Sleep changes	Fluid retention
Constipation	Swelling

- Yes
 - No
4. **Have you had an OFFICIAL diagnosis of hypothyroidism from a qualified medical doctor?**
 - Yes
 - No
 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
 - 2
 - 3
 - 4
 - 5
 - 6
 - 7
 - 8
 - 9
 - 10

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
- 7-12 months
- 1-5 years
- 5-10 years
- 10-15 years
- More than 15 years

7. Approximately how many times did you visit your GP with symptoms of hypothyroidism BEFORE you were given a diagnosis of hypothyroidism?

- 0
- 1
- 2-5
- 6-10
- 11-20
- 20-50
- 50+
- Can't remember

8. Were you prescribed any medications (excluding thyroid medications) for your symptoms BEFORE your diagnosis of hypothyroidism?

- Yes
- No

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
- Proton pump inhibitors (to reduce stomach acid)
- Painkillers
- Statins (to lower cholesterol)
- HRT (for menopause)
- Beta Blockers (to reduce heart rate)
- Tranquilisers (for anxiety)
- Medications for psychosis
- Medications for stabilizing mood
- Medications for high blood pressure
- Nifedipene (for Raynaud's phenomenon)

- Sleeping tablets
- Steroids – tablets, creams or injections (for arthritis/joint pain)
- Anticonvulsants
- Laxatives
- Dry skin
- Dry skin treatments
- Asthma inhaler
- Antihistamines
- Medications for dry eyes
- Other medications

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

- Congenital hypothyroidism
- Thyroidectomy
- Radio Active Iodine treatment
- Thyroid cancer
- Hashimoto's disease (autoimmune)
- Hypopituitarism
- I wasn't told the cause of my hypothyroidism
- Other (please specify)

11. Who FIRST diagnosed your hypothyroidism?

- NHS GP
- Private GP
- NHS Endocrinologist or Consultant
- Private Endocrinologist or Consultant
- Other (please specify)

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

- Yes
- No

13. What other condition(s)?

- Fibromyalgia (previously known as fibrositis)
- Depression
- ME/CFS
- Diabetes
- Gastritis
- Interstitial cystitis
- Infertility

- Rheumatoid arthritis
- Osteoarthritis
- Hypercholesterolemia (high cholesterol)
- Menopause
- Hypertension (high blood pressure)
- Heart problems
- Osteopenia/Osteoporosis
- Other (please specify)

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
- Painkillers
- Antidepressants
- Metformin
- Proton pump inhibitors (to reduce stomach acid)
- Antibiotics
- Medications for infertility
- Steroids – tablets, creams or injections (for arthritis/joint pain)
- Calcium for osteoporosis
- HRT
- Statins (to lower cholesterol)
- HRT (for menopause)
- Medications for high blood pressure
- Beta Blockers (to reduce heart rate)
- Sleeping tablets
- Other

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

- Yes
- No

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

- Yes
- No

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

- Up to £100

- £101 - £200
- £201 - £300
- £301 - £400
- £401 - £500
- £501 - £1000
- £1001 - £2000
- £2001 - £5000
- More than £5000
- I don't know, I didn't keep track

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

- Yes
- No

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

- Up to £100
- £101 - £200
- £201 - £300
- £301 - £400
- £401 - £500
- £501 - £1000
- £1001 - £2000
- £2001 - £5000
- More than £5000
- I don't know, I didn't keep track

20. Was your hypothyroidism diagnosed by thyroid testing?

- Yes
- No (i.e. I had a thyroidectomy)

21. What thyroid tests were done by your clinician to achieve diagnosis? (TSH; FT4 ;FT3; Thyroid; Peroxidase; Antibodies (TPO);Thyroglobulin Antibodies (TgAb); FT4/FT3; Urine test; Don't know)

- NHS GP
- Private GP
- NHS
- Endocrinologist/Consultant
- Private
- Endocrinologist/Consultant
- Other Practitioner/Clinician

22. Have you ever had thyroid testing refused?

- Yes
- No

23. Which tests were refused by your clinician and why? (NHS GP; Private GP; NHS Endocrinologist or Private Endocrinologist)

Which tests:

- TSH
- FT4
- FT3
- Thyroid
- Peroxidase
- Antibodies
- (TPO)
- Thyroglobulin
- Antibodies
- (TgAb)
- Reverse T3
- DIO2 gene

Why:

- Wasn't given a reason
- Not due another test yet
- No relevant symptoms
- Offered other tests first
- Policy of GP surgery/practice
- Hypothyroidism guidelines
- Cost
- Doctor said lab wouldn't do it
- Doctor requested and lab didn't do

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

- Yes
- No

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

- Less than 20 miles

- 20 - 100 miles
- 101 - 500 miles
- 501 - 1000 miles
- 1001 - 5000 miles
- More than 5000 miles
- I don't know

26. Approximately how much have you spent on visiting private GPs/Endocrinologists for your thyroid health? (Paid from my own funds; someone else paid for me or covered by medical insurance)

- Up to £100
- £101 - £200
- £201 - £300
- £301 - £400
- £401 - £500
- £501 - £1000
- £1001 - £2000
- £2001 - £5000
- More than £5000
- I don't know - I didn't keep track

27. Have you arranged your own PRIVATE THYROID TESTING?

- Yes
- No

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

- Up to £100
- £101 - £200
- £201 - £300
- £301 - £400
- £401 - £500
- £501 - £1000
- More than £1000
- I don't know - it was included in my consultation fee
- I don't know - I didn't keep track
- Other (please specify)

29. Did your NHS clinician tell you about the following thyroid medications? (GP; Endocrinologist; Thyroid surgeon; Other speciality clinician; I wasn't told about this)

- Levothyroxine (T4)

- Liothyronine (T3)
- Slow release T3
- Natural desiccated thyroid (NDT) – (Armour, NatureThroid, WP Thyroid, Erfa)
- Special order levothyroxine (lactose free; filler free; liquid)

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

- Yes
- No

31. Did your NHS clinician refuse to prescribe T3?

- Yes
- No

32. What was the reason for the refusal to prescribe T3? (NHS GP; NHS Endocrinologist or Consultant; Other NHS clinician)

- Budget constraints
- Didn't know anything about this medication
- Not in the British National Formulary
- Royal College of Physician's Guidance
- Would like to but not allowed
- Clinical Commissioning Group policy
- PCT policy Health Board policy
- Would not accept recommendation to prescribe from a private clinician
- Would not give a reason
- I can't remember the reason
- No evidence of superiority over levothyroxine
- Concerns about potential harm to patients
- Other reason for refusing

33. Did you ask your NHS clinician to prescribe slow release T3?

- Yes
- No

34. Did your NHS clinician refuse to prescribe slow release T3?

- Yes
- No

35. What was the reason for the refusal to prescribe slow release T3? (NHS GP; NHS Endocrinologist or Consultant; Other NHS clinician)

- Budget constraints
- Didn't know anything about this medication
- Not in the British National Formulary
- Royal College of Physician's Guidance
- Would like to but not allowed
- Clinical Commissioning Group policy
- PCT policy
- Health Board policy
- Would not accept recommendation to prescribe from a private clinician
- Would not give a reason
- I can't remember the reason
- No evidence of superiority over levothyroxine
- Concerns about potential harm to patients
- Other reason for refusing

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

- Yes
- No

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

- Yes
- No

38. What was the reason for the refusal to prescribe natural desiccated thyroid? (NHS GP; NHS Endocrinologist or Consultant; Other NHS clinician)

- Budget constraints
- Didn't know anything about this medication
- Not in the British National Formulary
- Royal College of Physician's Guidance
- Would like to but not allowed
- Clinical Commissioning Group policy
- PCT policy
- Health Board policy
- Would not accept recommendation to prescribe from a private clinician
- Would not give a reason
- I can't remember the reason
- No evidence of superiority over levothyroxine
- Concerns about potential harm to patients
- Other reason for refusing

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

- Yes
- No

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

- Yes
- No

41. What was the reason for the refusal to prescribe a special order levothyroxine? (NHS GP; NHS Endocrinologist or Consultant; Other NHS clinician)

- Budget constraints
- Didn't know anything about this medication
- Not in the British National Formulary
- Royal College of Physician's Guidance
- Would like to but not allowed
- Clinical Commissioning Group policy
- PCT policy
- Health Board policy
- Would not accept recommendation to prescribe from a private clinician
- Would not give a reason
- I can't remember the reason
- No evidence of superiority over levothyroxine
- Concerns about potential harm to patients
- Other reason for refusing

42. Are you CURRENTLY taking medication for your hypothyroidism?

- Yes
- No

43. What thyroid medications are you currently taking? (Prescribed by my NHS GP (NHS prescription); Prescribed by my NHS GP (private prescription); Prescribed by my private GP; Prescribed by my NHS endocrinologist/consultant; Prescribed by my private endocrinologist/consultant; Purchase it myself online (without an NHS prescription); Obtaining it some other way

- Levothyroxine (T4)

- Liothyronine (T3)
- Slow release T3
- Natural desiccated thyroid (NDT)
- Special order levothyroxine i.e. lactose free, filler free etc.
- Glandulars/thyroid extract

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

- Yes
- No

45. Which thyroid medication improved your hypothyroid symptoms? (Totally Significantly Slightly Not at all Briefly)

- Levothyroxine (T4) only
- Liothyronine (T3) only
- Combination of levothyroxine (T4) and liothyronine (T3)
- Slow release T3 only
- Combination of levothyroxine (T4) and slow release T3
- Natural desiccated thyroid (NDT) only
- Combination of natural desiccated thyroid (NDT) and levothyroxine (T4)
- Combination of natural desiccated thyroid (NDT) and liothyronine (T3)
- Combination of natural desiccated thyroid (NDT) and levothyroxine (T4) and liothyronine (T3)
- Special order levothyroxine i.e. lactose free, filler free etc.
- Glandulars/thyroid extract
- Other thyroid medication/combination

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
- Social life
- Working life

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
- Yes, my non thyroid prescription medications decreased
- No, my non thyroid prescription medications stayed the same
- No, my non thyroid prescription medications increased

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

I was on:

- More than 10 non thyroid prescription meds
- 10 non thyroid prescription meds
- 9 non thyroid prescription meds
- 8 non thyroid prescription meds
- 7 non thyroid prescription meds
- 6 non thyroid prescription meds
- 5 non thyroid prescription meds
- 4 non thyroid prescription meds
- 3 non thyroid prescription meds
- 2 non thyroid prescription meds
- 1 non thyroid prescription meds

I am now on:

- 0 non thyroid prescription meds
- 1 non thyroid prescription meds
- 2 non thyroid prescription meds
- 3 non thyroid prescription meds
- 4 non thyroid prescription meds
- 5 non thyroid prescription meds
- 6 non thyroid prescription meds
- 7 non thyroid prescription meds
- 8 non thyroid prescription meds
- 9 non thyroid prescription meds
- 10 non thyroid prescription meds

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

- Yes, even though it was improving my symptoms
- Yes, although it wasn't really helping anyway
- No

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? Why was it refused? When was it refused?)

- Liothyronine (T3)
- Natural desiccated thyroid (NDT)

- Special order levothyroxine
- Slow Release T3
- Other thyroid Medication

Refused by:

- GP
- Endocrinologist/Consultant
- Other
- Why was it refused:
- Cost
- Change of doctor
- PCT refused
- Health Board refused
- CCG refused
- New surgery policy
- Head partner said no
- Don't know

When was it refused:

- Within the last three months
- Three to six months ago
- Six months to a year ago
- Over a year ago
- Can't remember

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
- I was refused by the Clinical Commissioning Group/Health Board below:

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

Problems:

- I've never had a problem with supply
- Manufacturer recall
- Manufacturer licence withdrawal
- Discontinued by manufacturer
- Informed by pharmacy that no longer available
- Problem with manufacture

- Shortage of supply
- Problems getting same brand
- I don't know the reason
- Not being prescribed on NHS

Medications:

- Levothyroxine (T4)
- Liothyronine (T3)
- Natural desiccated thyroid (NDT)
- Special order Levothyroxine

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

- Yes
- No

54. Approximately how much per month are you or were you spending on your * THYROID medication? (Up to £10; £11 - £20; £21 - £30; £31 - £40; £41 - £50; £51 - £100; More than £100)

- Levothyroxine (T4)
- Liothyronine (T3) Natural desiccated thyroid (NDT)
- Other thyroid medication

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

- Yes
- Yes and he is monitoring me
- No

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

- Yes, with my NHS GP
- Yes, with my NHS Endocrinologist/Consultant
- No, my NHS GP was not open to discussion
- No, my NHS Endocrinologist/Consultant was not open to discussion
- I didn't discuss this with my NHS GP
- I didn't discuss this with my NHS Endocrinologist/Consultant
- Other (please specify)

57. How would you rate your NHS GP's knowledge of the following? Please

choose an option from each. (Poor; Good; Very Good; Didn't discuss this at all).

- Hypothyroidism
- Testing options
- Liothyronine (T3)
- Natural desiccated thyroid (NDT)

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
- Budget
- Time
- Guidelines
- Other (please specify)

59. Were you given any information about thyroid disease by your NHS clinician? (NHS GP NHS Endocrinologist/Consultant)

- Verbal information on my hypothyroidism
- Given an NHS leaflet about hypothyroidism
- Given verbal or printed information about Thyroid UK
- Given verbal or printed information about another support group
- Was advised to visit NHS Choices
- Was advised not to go looking on the internet for information
- I wasn't given any information about my hypothyroidism
- Other

60. Did your NHS clinician treat you with dignity and respect? (GP; Endocrinologist; Other NHS Clinician)

- Yes
- No
- Sometimes

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

- I didn't ask for a referral
- I asked and was refused
- I asked and I got my referral
- Other (please specify)

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
- Antidepressants
- Proton pump inhibitors (to reduce stomach acid)
- Painkillers
- Statins (to lower cholesterol)
- HRT (for menopause)
- Beta blockers (to reduce heart rate)
- Tranquilisers (for anxiety)
- Medications for psychosis
- Medications for stabilizing mood
- Medications for high blood pressure
- Nifedipine (for Raynaud's phenomenon)
- Sleeping tablets
- Steroids - tablets, creams or injections (for arthritis/joint pain etc)
- Anticonvulsants
- Laxatives
- Dry skin treatments
- Asthma inhaler
- Antihistamines
- Medications for dry eyes
- Other medication(s)

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

- Once a week
- More than once a week
- Once a fortnight
- Once a month
- More than once a month
- Once every few months
- Less than once a year
- Other (please specify)

64. Have you been diagnosed with any health conditions?

- Yes
- No

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

66. Are you a paying member of Thyroid UK?

- Yes
- No