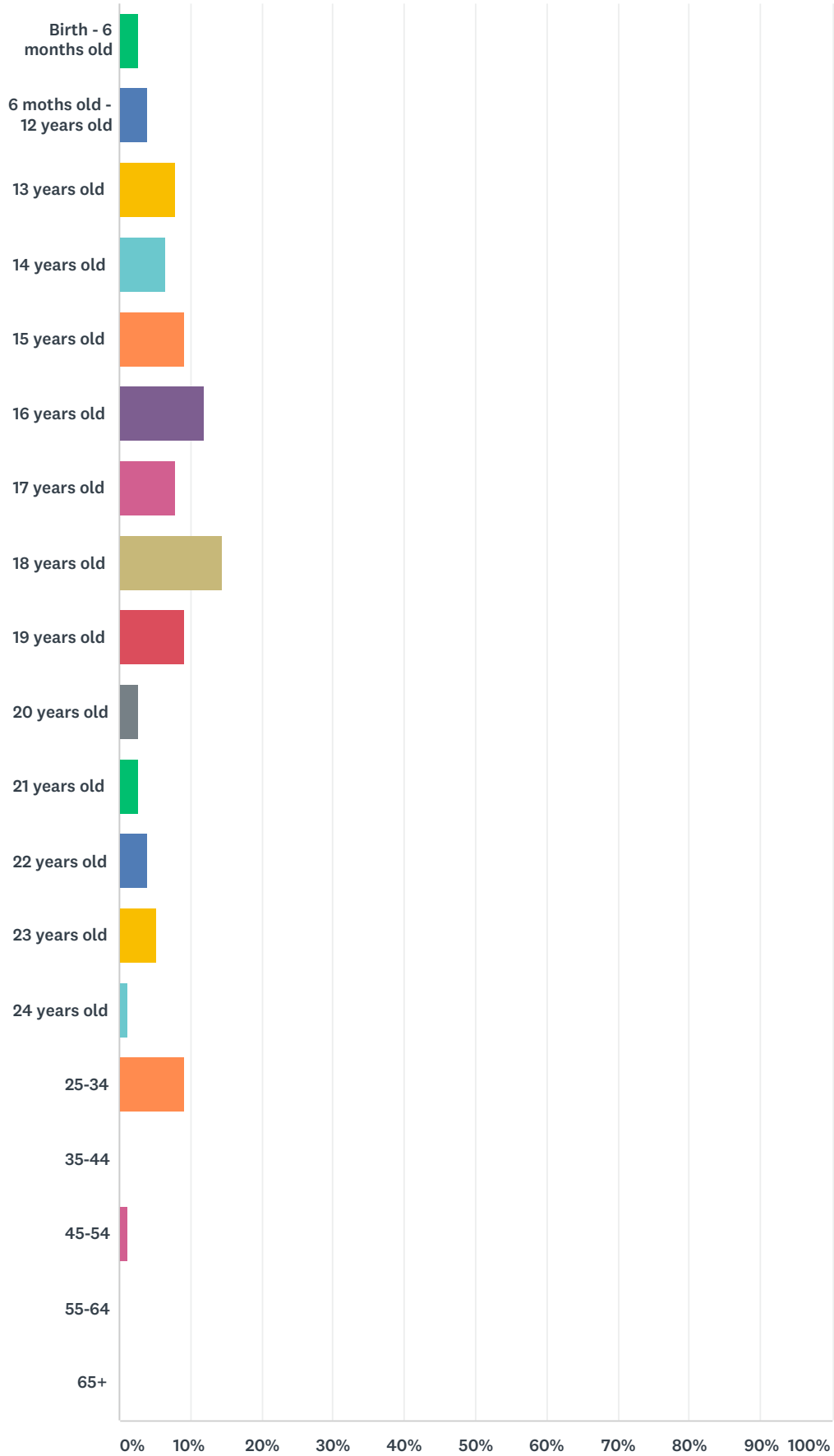


Q1 How old were you when first diagnosed.

Answered: 76 Skipped: 28



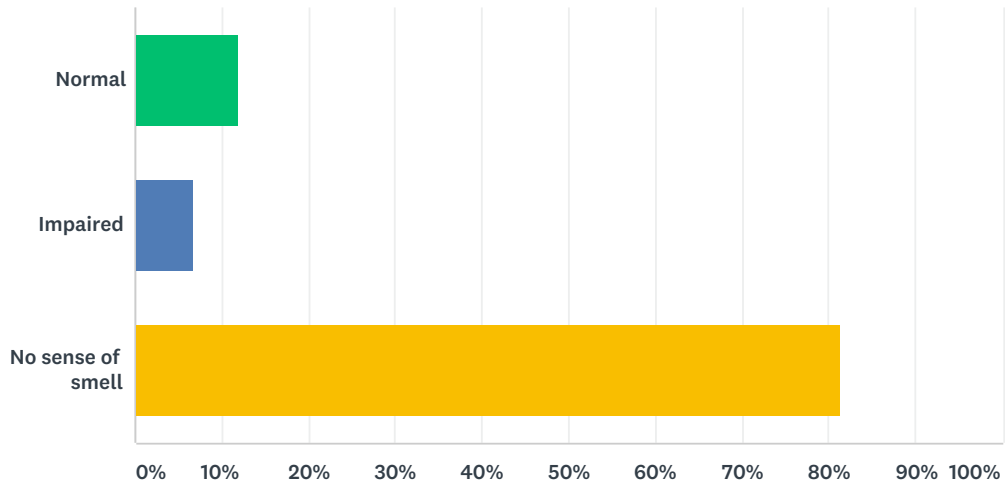
ANSWER CHOICES

RESPONSES

Birth - 6 months old	2.63%	2
6 months old - 12 years old	3.95%	3
13 years old	7.89%	6
14 years old	6.58%	5
15 years old	9.21%	7
16 years old	11.84%	9
17 years old	7.89%	6
18 years old	14.47%	11
19 years old	9.21%	7
20 years old	2.63%	2
21 years old	2.63%	2
22 years old	3.95%	3
23 years old	5.26%	4
24 years old	1.32%	1
25-34	9.21%	7
35-44	0.00%	0
45-54	1.32%	1
55-64	0.00%	0
65+	0.00%	0
TOTAL		76

Q2 How is your sense of smell

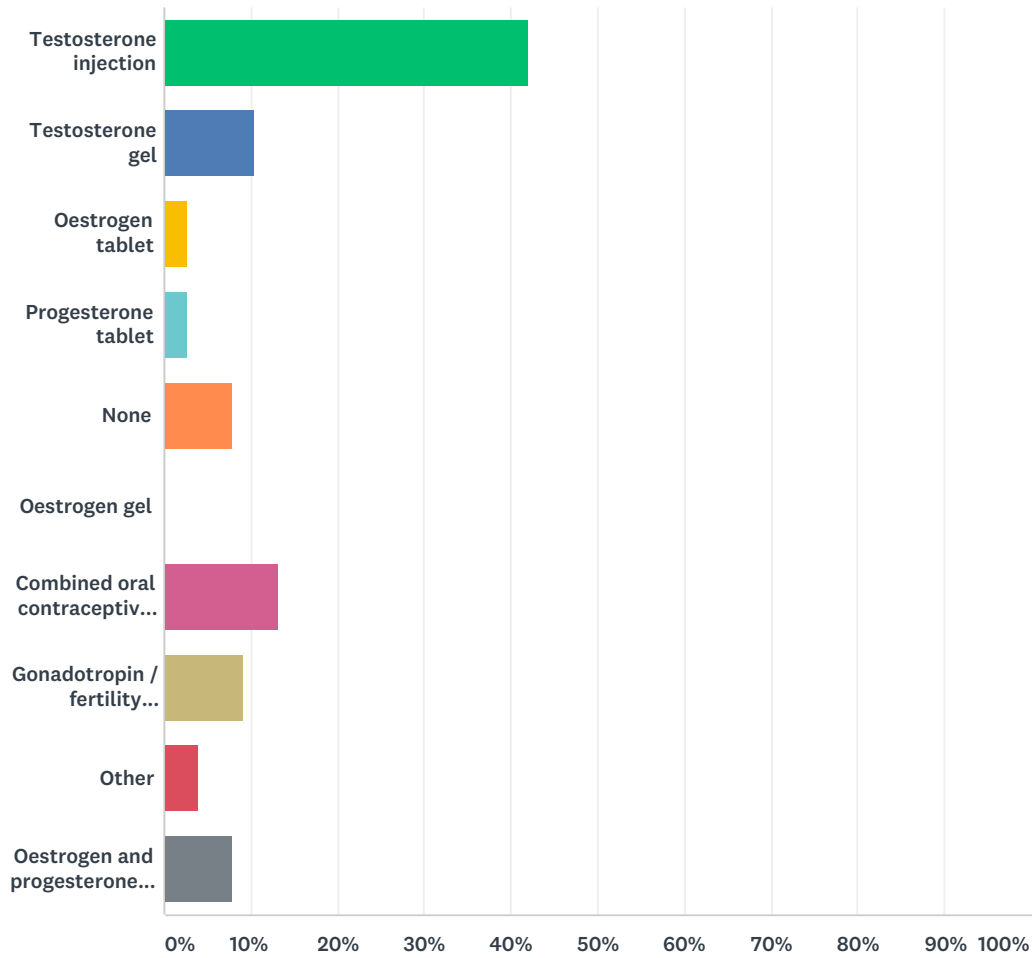
Answered: 75 Skipped: 29



ANSWER CHOICES	RESPONSES
Normal	12.00% 9
Impaired	6.67% 5
No sense of smell	81.33% 61
TOTAL	75

Q3 What form of hormone replacement therapy are you on

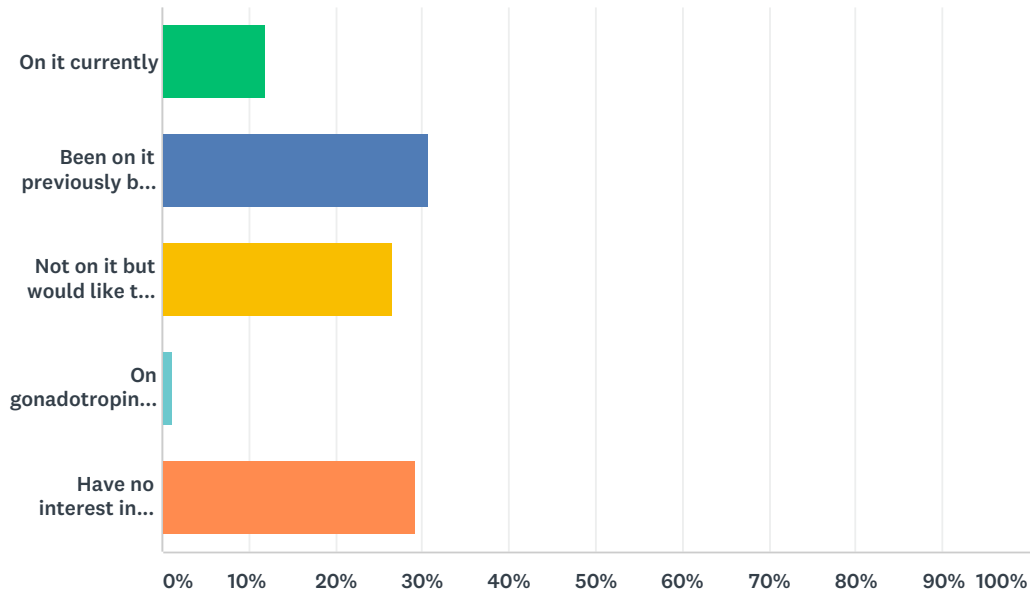
Answered: 76 Skipped: 28



ANSWER CHOICES	RESPONSES	
Testosterone injection	42.11%	32
Testosterone gel	10.53%	8
Oestrogen tablet	2.63%	2
Progesterone tablet	2.63%	2
None	7.89%	6
Oestrogen gel	0.00%	0
Combined oral contraceptive pill	13.16%	10
Gonadotropin / fertility treatment	9.21%	7
Other	3.95%	3
Oestrogen and progesterone taken separately	7.89%	6
TOTAL		76

Q4 Have you been on gonadotropin or fertility treatment

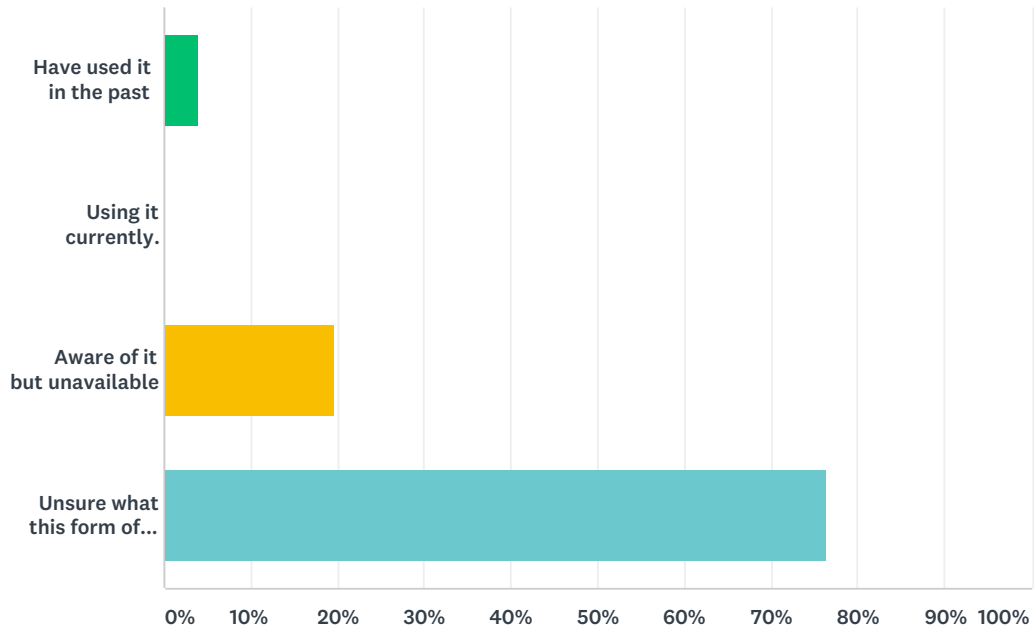
Answered: 75 Skipped: 29



ANSWER CHOICES	RESPONSES	
On it currently	12.00%	9
Been on it previously but not currently	30.67%	23
Not on it but would like to try if available	26.67%	20
On gonadotropin therapy for testosterone replacement only	1.33%	1
Have no interest in this form of treatment	29.33%	22
TOTAL		75

Q5 Have you heard of GnRH pulsatile therapy

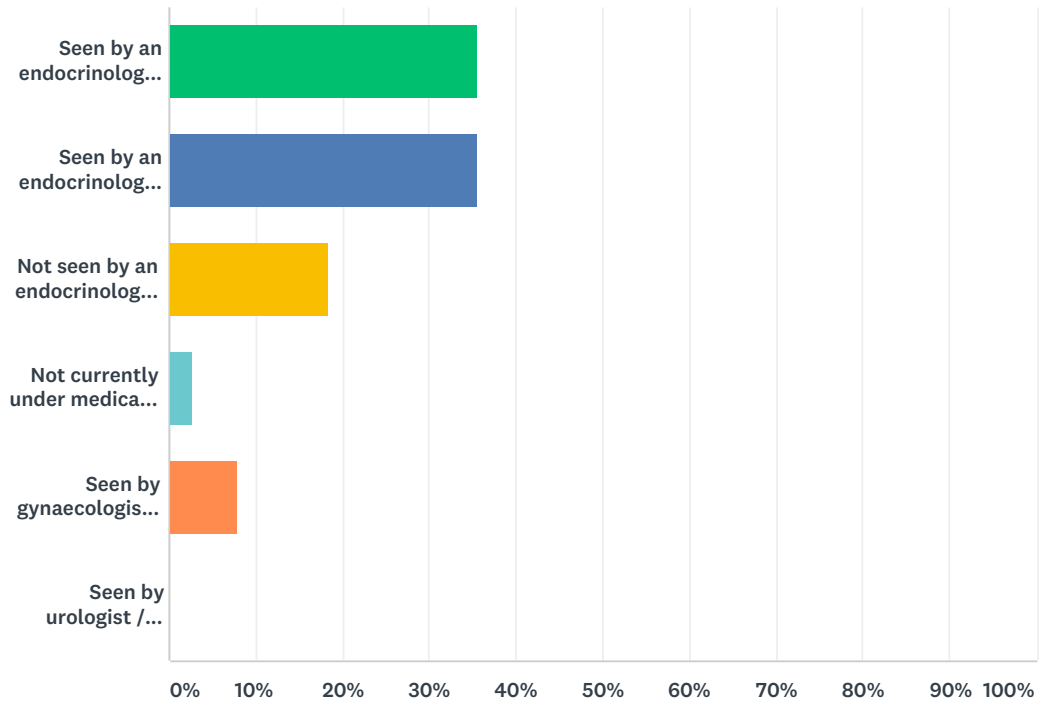
Answered: 76 Skipped: 28



ANSWER CHOICES	RESPONSES	
Have used it in the past	3.95%	3
Using it currently.	0.00%	0
Aware of it but unavailable	19.74%	15
Unsure what this form of therapy entails.	76.32%	58
TOTAL		76

Q6 Are you seen by an endocrinologist or general physician

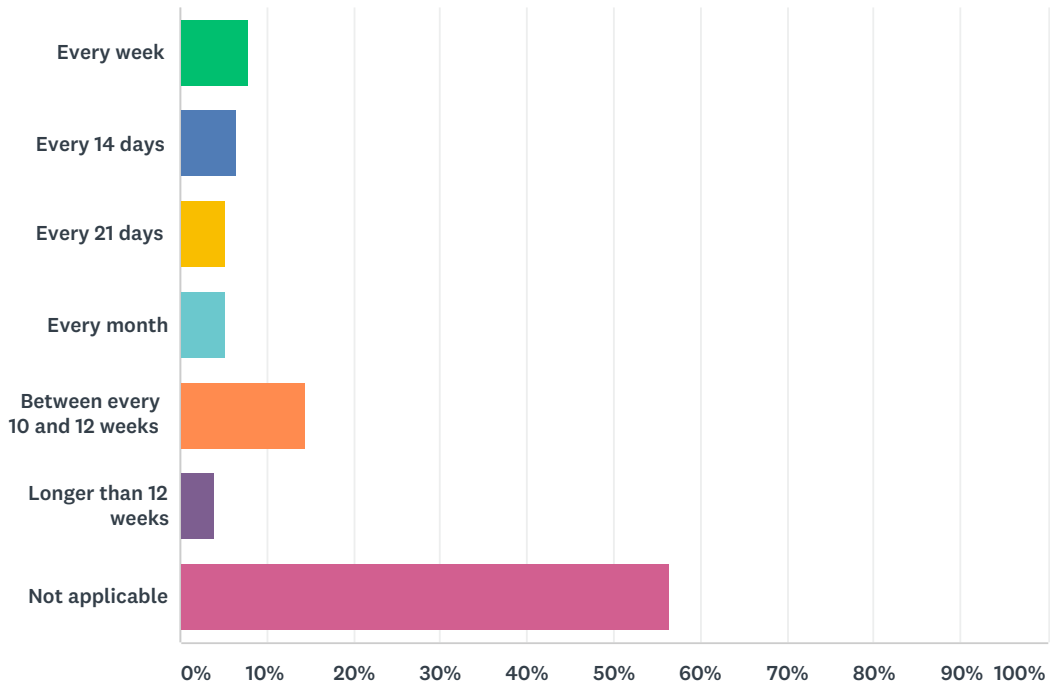
Answered: 76 Skipped: 28



ANSWER CHOICES	RESPONSES	
Seen by an endocrinologist who has specialised knowledge of KS / CHH	35.53%	27
Seen by an endocrinologist with no apparent specialised knowledge of KS / CHH	35.53%	27
Not seen by an endocrinologist, seen by local care doctor only	18.42%	14
Not currently under medical care	2.63%	2
Seen by gynaecologist only	7.89%	6
Seen by urologist / andrologist only.	0.00%	0
TOTAL		76

Q7 If taking testosterone injections how often do you have the injection

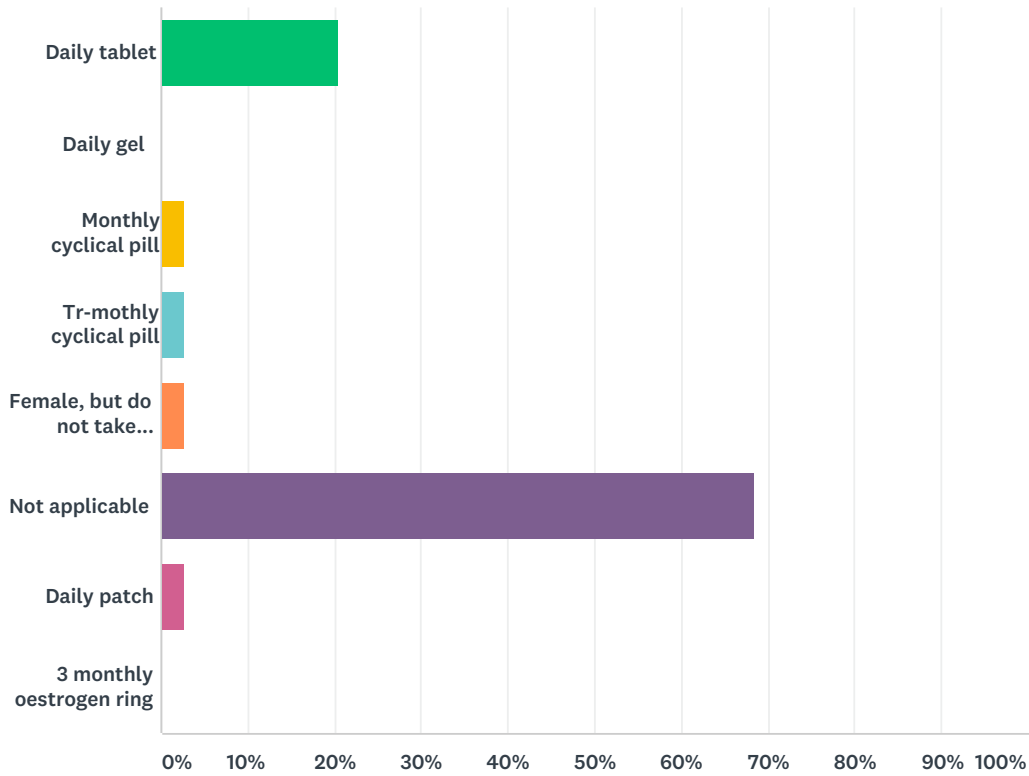
Answered: 76 Skipped: 28



ANSWER CHOICES	RESPONSES	
Every week	7.89%	6
Every 14 days	6.58%	5
Every 21 days	5.26%	4
Every month	5.26%	4
Between every 10 and 12 weeks	14.47%	11
Longer than 12 weeks	3.95%	3
Not applicable	56.58%	43
TOTAL		76

Q8 If taking oestrogen, what method are you using

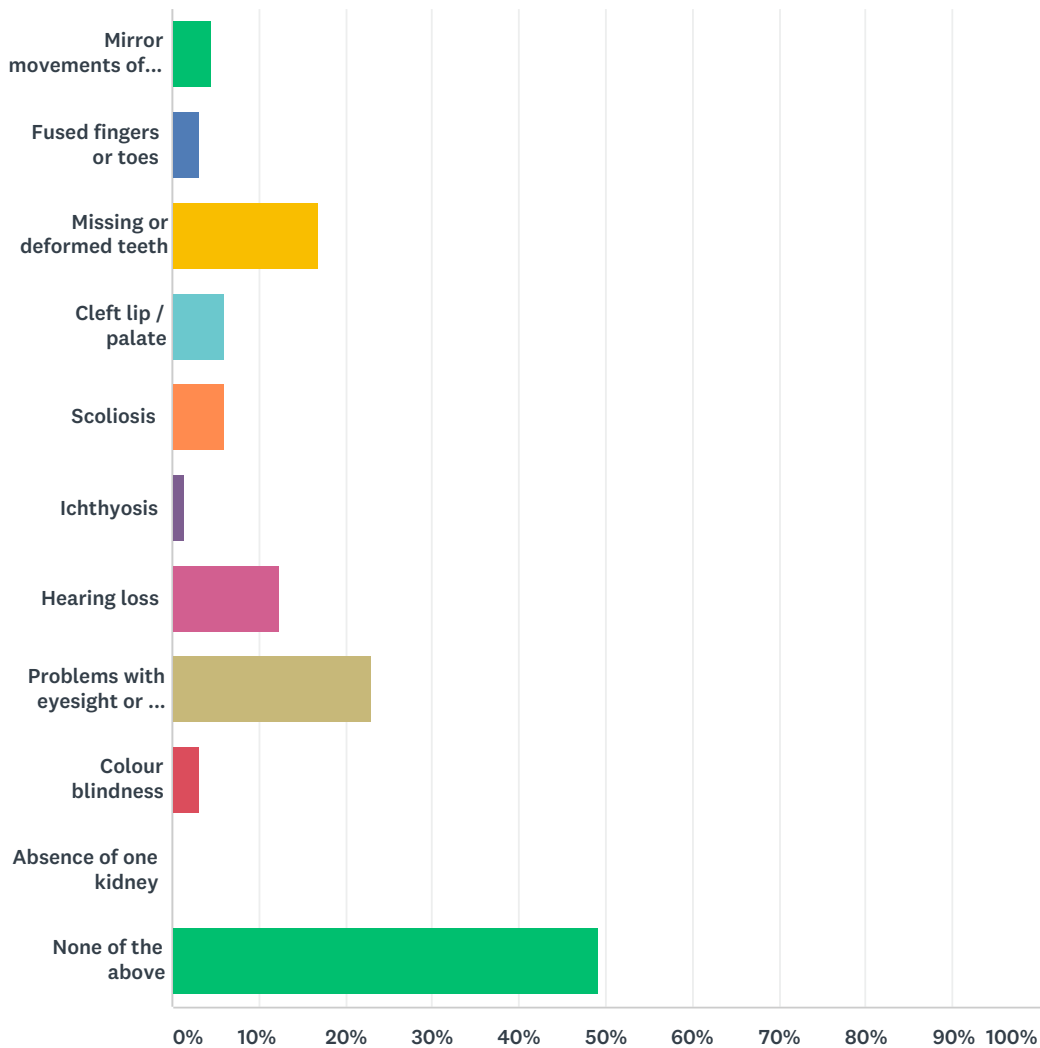
Answered: 73 Skipped: 31



ANSWER CHOICES	RESPONSES	
Daily tablet	20.55%	15
Daily gel	0.00%	0
Monthly cyclical pill	2.74%	2
Tr-monthly cyclical pill	2.74%	2
Female, but do not take oestrogen treatment	2.74%	2
Not applicable	68.49%	50
Daily patch	2.74%	2
3 monthly oestrogen ring	0.00%	0
TOTAL		73

Q9 Apart from delayed or absent puberty and / or anosmia what othersymptoms do you have ?

Answered: 65 Skipped: 39



ANSWER CHOICES	RESPONSES
Mirror movements of the hands	4.62% 3
Fused fingers or toes	3.08% 2
Missing or deformed teeth	16.92% 11
Cleft lip / palate	6.15% 4
Scoliosis	6.15% 4
Ichthyosis	1.54% 1
Hearing loss	12.31% 8
Problems with eyesight or eye movement	23.08% 15
Colour blindness	3.08% 2

Absence of one kidney	0.00%	0
None of the above	49.23%	32
Total Respondents: 65		