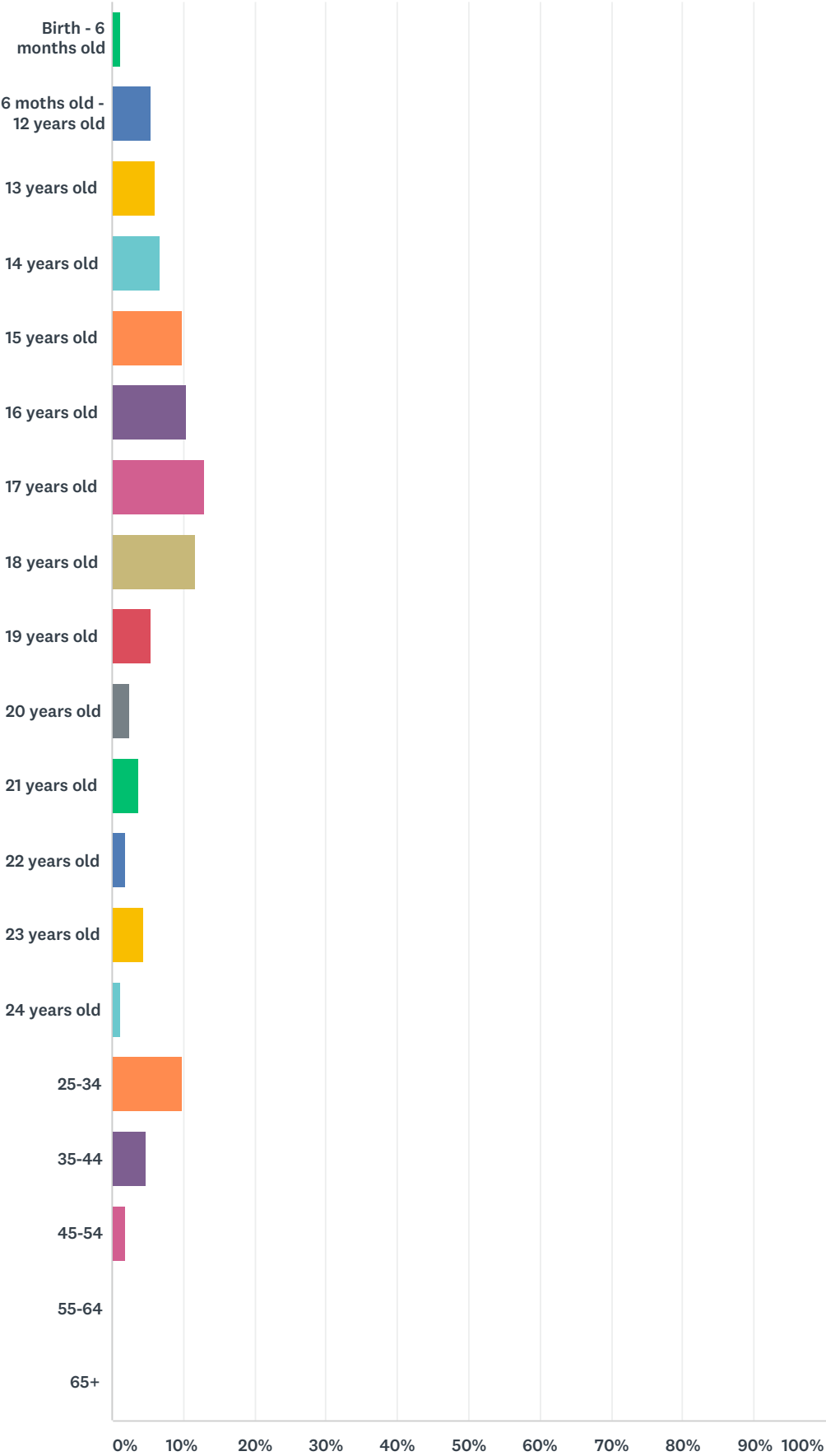


Q1 How old were you when first diagnosed.

Answered: 163 Skipped: 28



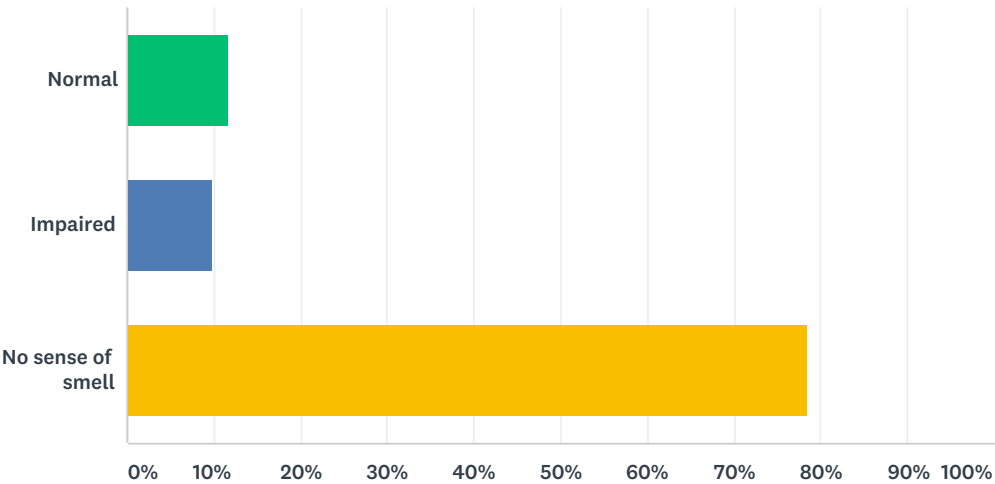
ANSWER CHOICES

RESPONSES

Birth - 6 months old	1.23%	2
6 months old - 12 years old	5.52%	9
13 years old	6.13%	10
14 years old	6.75%	11
15 years old	9.82%	16
16 years old	10.43%	17
17 years old	12.88%	21
18 years old	11.66%	19
19 years old	5.52%	9
20 years old	2.45%	4
21 years old	3.68%	6
22 years old	1.84%	3
23 years old	4.29%	7
24 years old	1.23%	2
25-34	9.82%	16
35-44	4.91%	8
45-54	1.84%	3
55-64	0.00%	0
65+	0.00%	0
TOTAL		163

Q2 How is your sense of smell

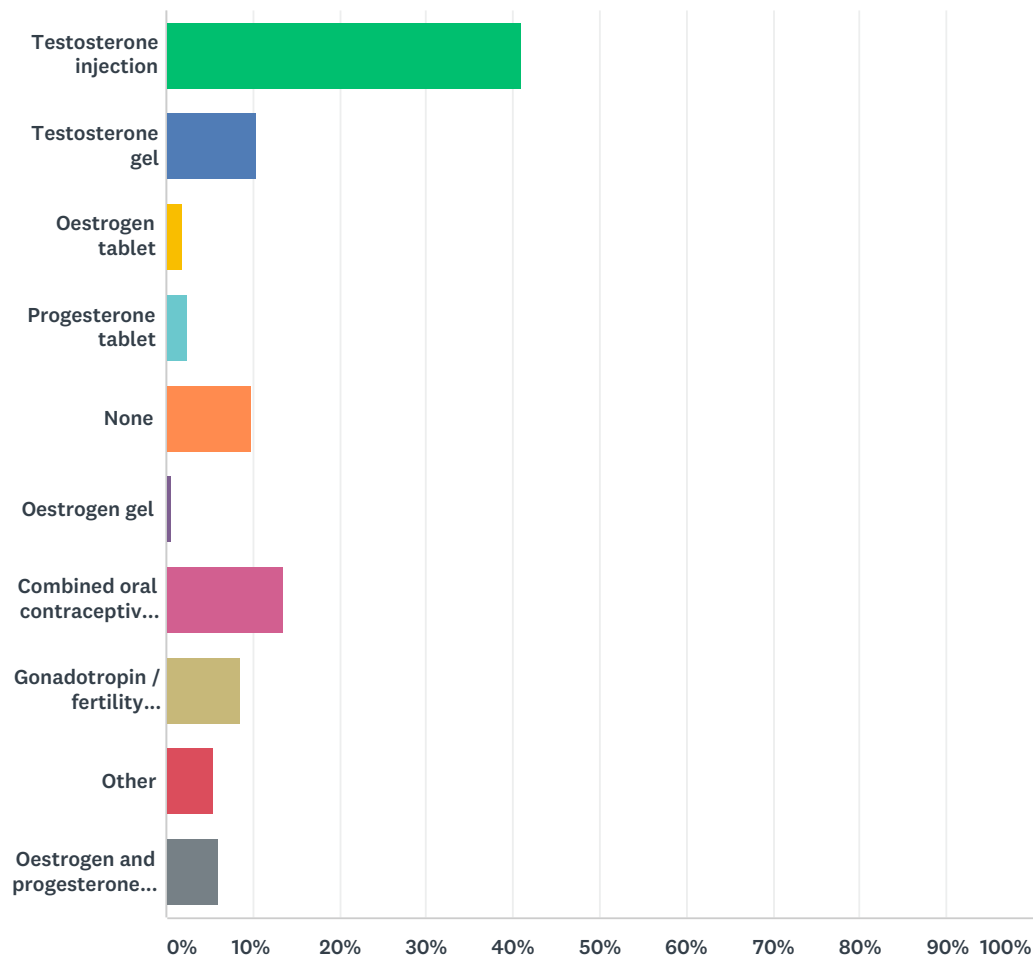
Answered: 162 Skipped: 29



ANSWER CHOICES		RESPONSES	
Normal		11.73%	19
Impaired		9.88%	16
No sense of smell		78.40%	127
TOTAL			162

Q3 What form of hormone replacement therapy are you on

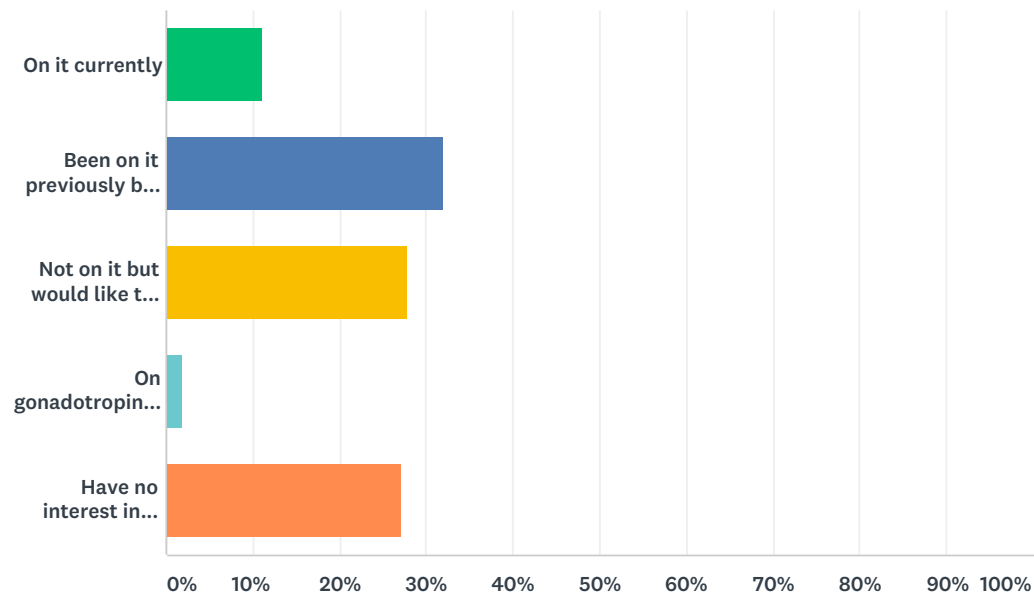
Answered: 163 Skipped: 28



ANSWER CHOICES	RESPONSES	
Testosterone injection	41.10%	67
Testosterone gel	10.43%	17
Oestrogen tablet	1.84%	3
Progesterone tablet	2.45%	4
None	9.82%	16
Oestrogen gel	0.61%	1
Combined oral contraceptive pill	13.50%	22
Gonadotropin / fertility treatment	8.59%	14
Other	5.52%	9
Oestrogen and progesterone taken separately	6.13%	10
TOTAL		163

Q4 Have you been on gonadotropin or fertility treatment

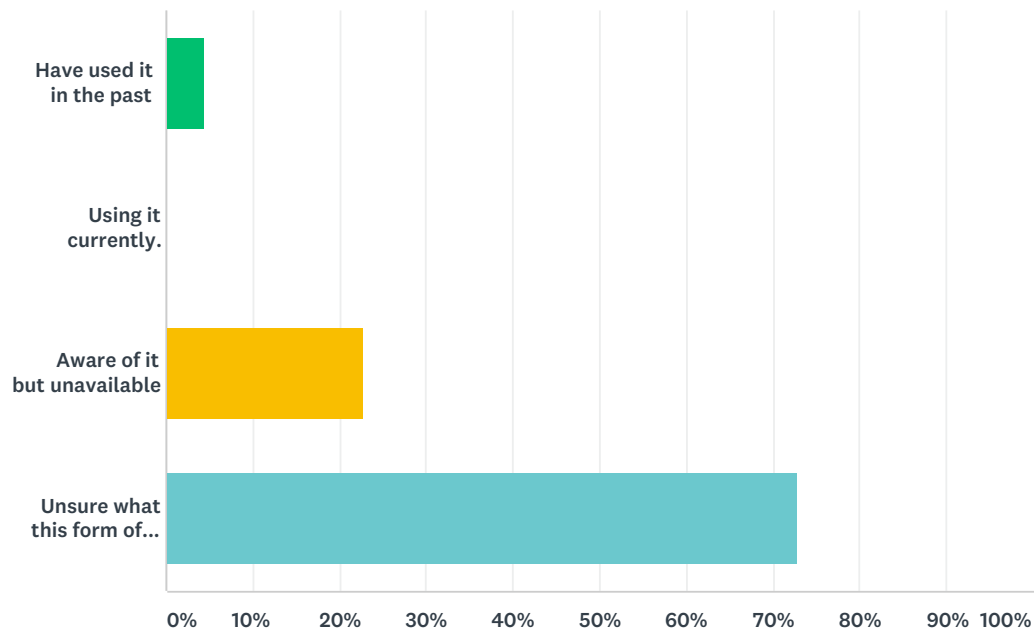
Answered: 162 Skipped: 29



ANSWER CHOICES		RESPONSES	
On it currently		11.11%	18
Been on it previously but not currently		32.10%	52
Not on it but would like to try if available		27.78%	45
On gonadotropin therapy for testosterone replacement only		1.85%	3
Have no interest in this form of treatment		27.16%	44
TOTAL			162

Q5 Have you heard of GnRH pulsatile therapy

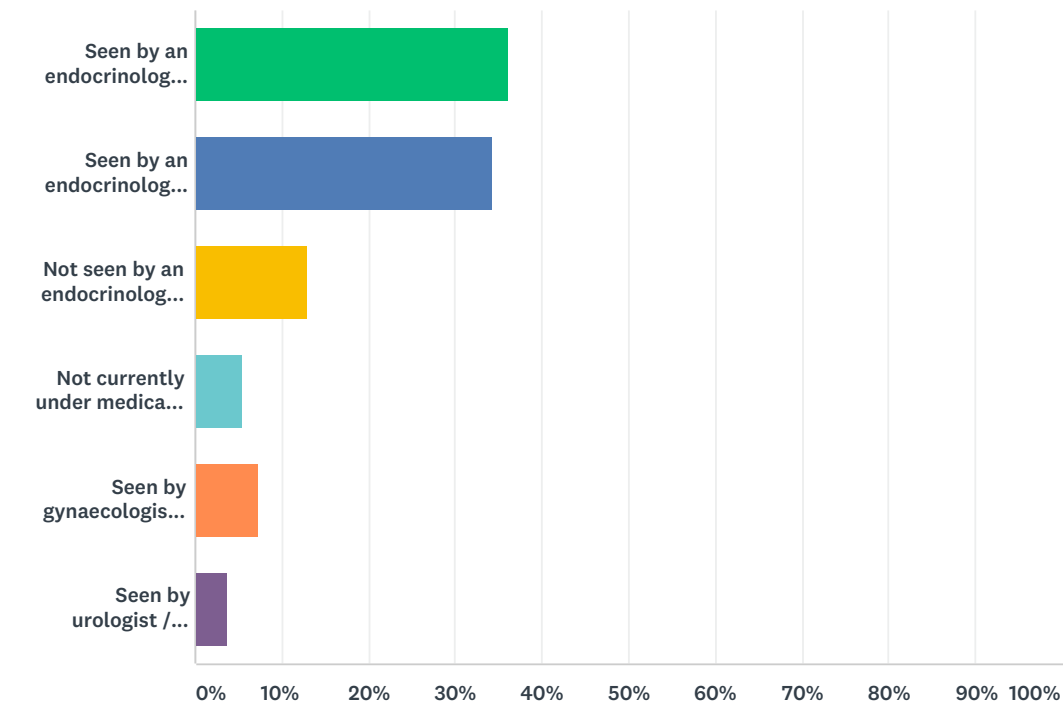
Answered: 162 Skipped: 29



ANSWER CHOICES	RESPONSES	
Have used it in the past	4.32%	7
Using it currently.	0.00%	0
Aware of it but unavailable	22.84%	37
Unsure what this form of therapy entails.	72.84%	118
TOTAL		162

Q6 Are you seen by an endocrinologist or general physician

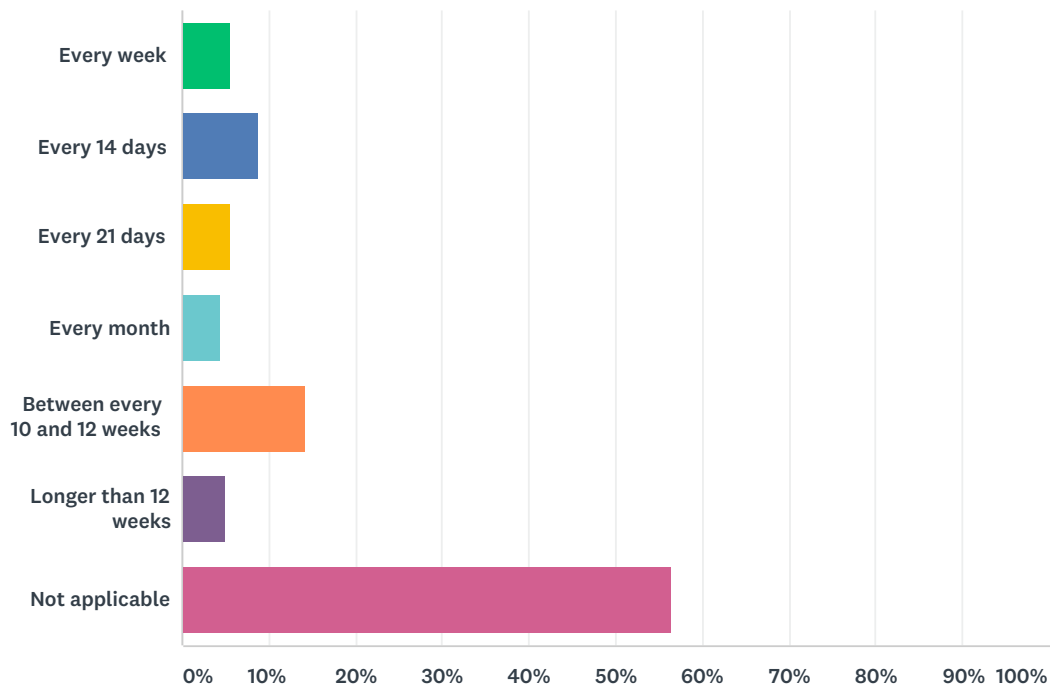
Answered: 163 Skipped: 28



ANSWER CHOICES	RESPONSES	
Seen by an endocrinologist who has specialised knowledge of KS / CHH	36.20%	59
Seen by an endocrinologist with no apparent specialised knowledge of KS / CHH	34.36%	56
Not seen by an endocrinologist, seen by local care doctor only	12.88%	21
Not currently under medical care	5.52%	9
Seen by gynaecologist only	7.36%	12
Seen by urologist / andrologist only.	3.68%	6
TOTAL		163

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

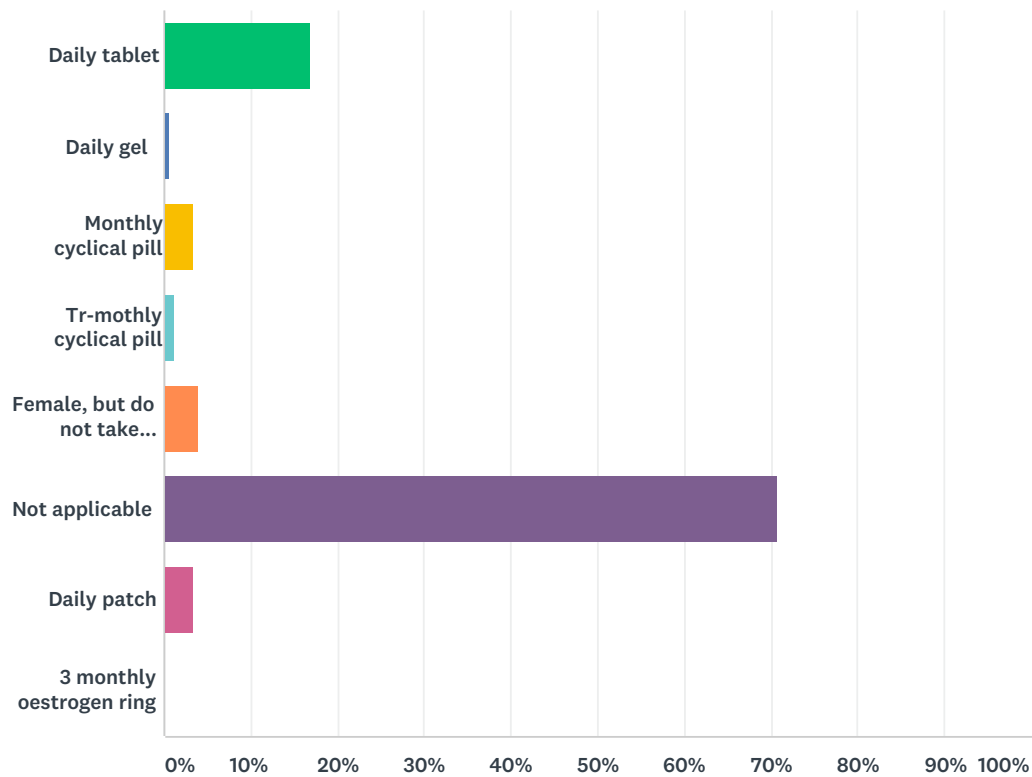
Answered: 161 Skipped: 30



ANSWER CHOICES	RESPONSES	
Every week	5.59%	9
Every 14 days	8.70%	14
Every 21 days	5.59%	9
Every month	4.35%	7
Between every 10 and 12 weeks	14.29%	23
Longer than 12 weeks	4.97%	8
Not applicable	56.52%	91
TOTAL		161

Q8 If taking oestrogen, what method are you using

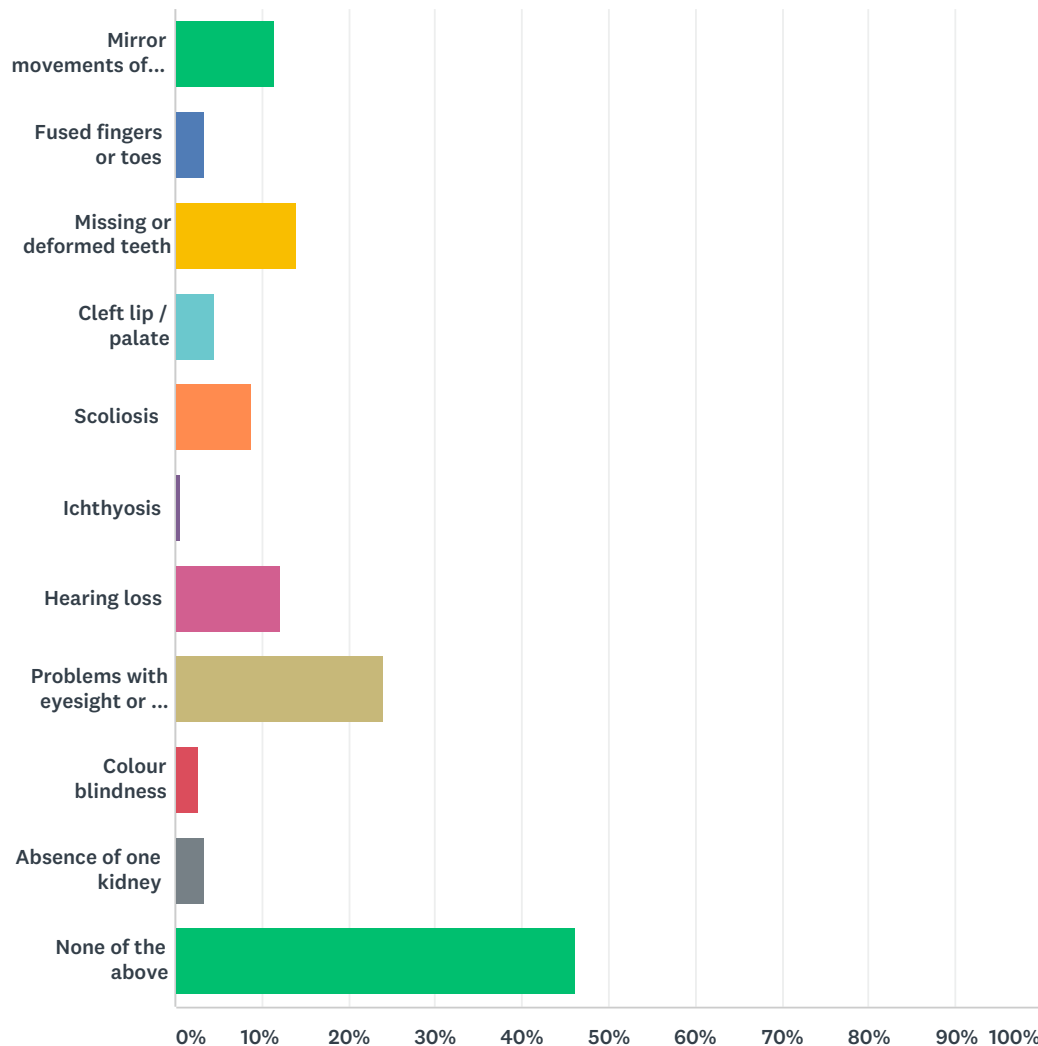
Answered: 154 Skipped: 37



ANSWER CHOICES	RESPONSES	
Daily tablet	16.88%	26
Daily gel	0.65%	1
Monthly cyclical pill	3.25%	5
Tr-mothly cyclical pill	1.30%	2
Female, but do not take oestrogen treatment	3.90%	6
Not applicable	70.78%	109
Daily patch	3.25%	5
3 monthly oestrogen ring	0.00%	0
TOTAL		154

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

Answered: 149 Skipped: 42



ANSWER CHOICES	RESPONSES	
Mirror movements of the hands	11.41%	17
Fused fingers or toes	3.36%	5
Missing or deformed teeth	14.09%	21
Cleft lip / palate	4.70%	7
Scoliosis	8.72%	13
Ichthyosis	0.67%	1
Hearing loss	12.08%	18
Problems with eyesight or eye movement	24.16%	36
Colour blindness	2.68%	4

Absence of one kidney	3.36%	5
None of the above	46.31%	69
Total Respondents: 149		