

## Huntington's NSW & ACT survey

**We would be very grateful if you would take 5 minutes to complete this survey. Your confidential input will help us to remain focussed on your needs and desires as much as possible.**

Monday, July 29, 2019

# 153

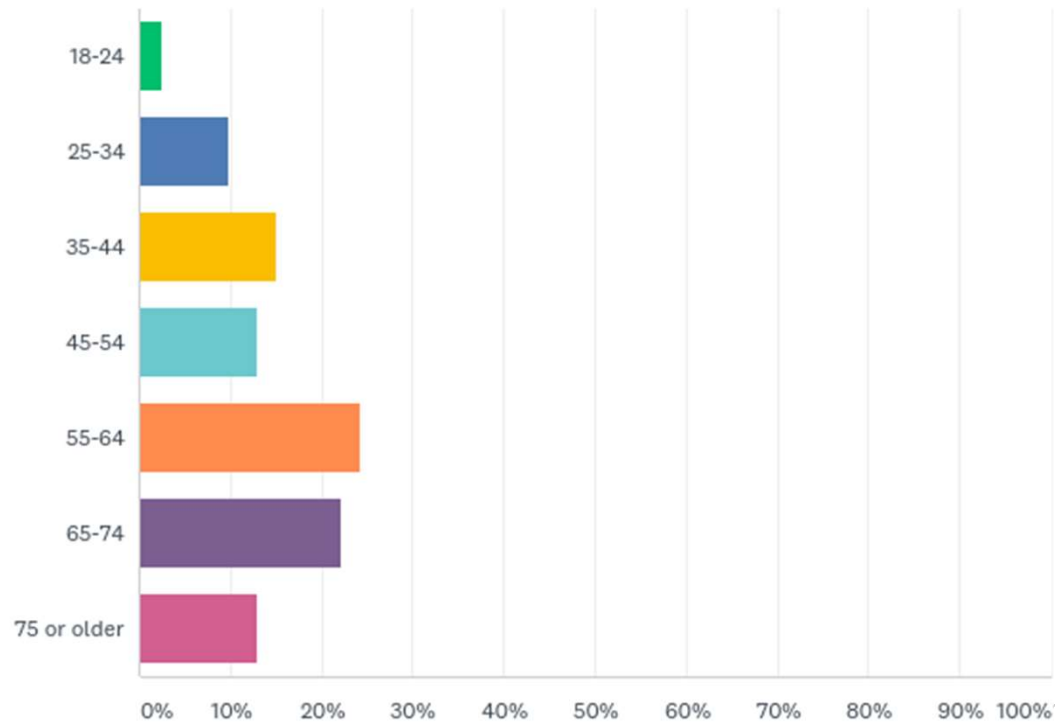
Total Responses

Date Created: Friday, March 22, 2019

Complete Responses: 153

# Q1: 1. What is your age?

Answered: 153 Skipped: 0



## Q1: 1. What is your age?

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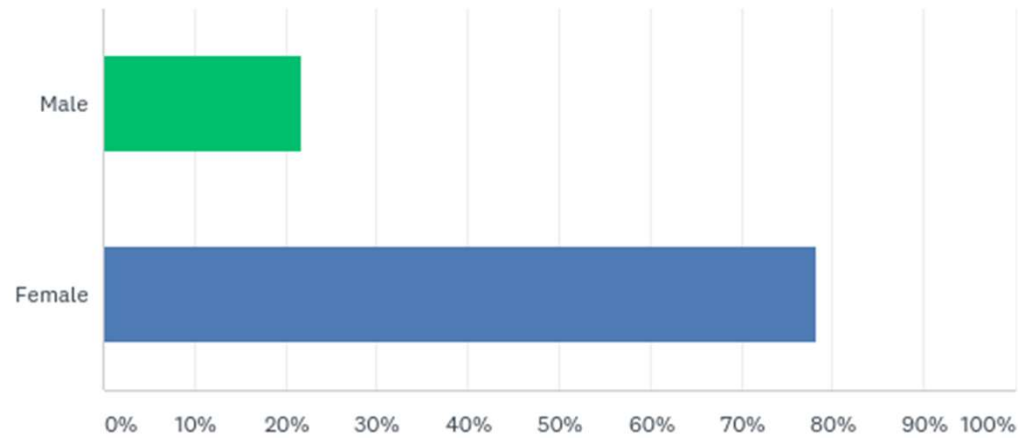
Answered: 153 Skipped: 0

ANSWER CHOICES	RESPONSES
18-24	2.61% 4
25-34	9.80% 15
35-44	15.03% 23
45-54	13.07% 20
55-64	24.18% 37
65-74	22.22% 34
75 or older	13.07% 20
<b>TOTAL</b>	<b>153</b>

## Q2: What is your gender & postcode?

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Answered: 151 Skipped: 2



## Q2: What is your gender & postcode?

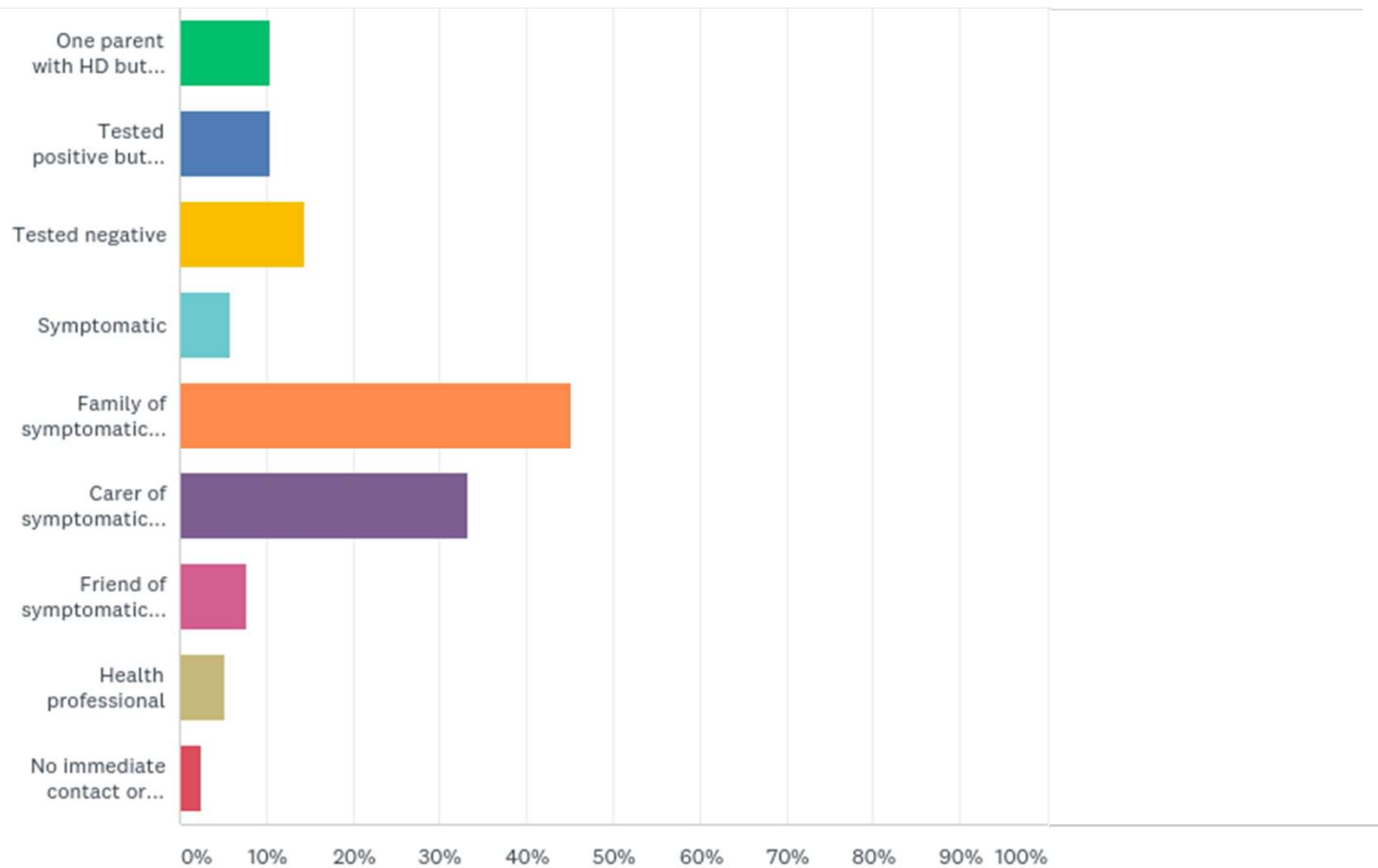
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Answered: 151 Skipped: 2

ANSWER CHOICES	RESPONSES	
Male	21.85%	33
Female	78.15%	118
TOTAL		151

### Q3: What is your relationship to Huntington's disease? (You can tick more than one box.)

Answered: 153 Skipped: 0



### Q3: What is your relationship to Huntington's disease? (You can tick more than one box.)

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Answered: 153 Skipped: 0

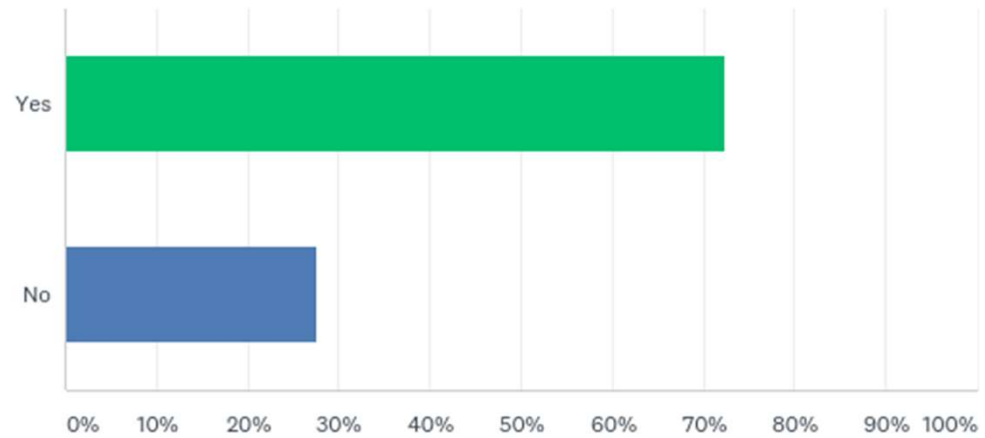
ANSWER CHOICES	RESPONSES	
One parent with HD but your own status unknown	10.46%	16
Tested positive but not yet symptomatic	10.46%	16
Tested negative	14.38%	22
Symptomatic	5.88%	9
Family of symptomatic person	45.10%	69
Carer of symptomatic person	33.33%	51
Friend of symptomatic person	7.84%	12
Health professional	5.23%	8
No immediate contact or involvement	2.61%	4
Total Respondents: 153		



## Q4: Are you a member of Huntington's NSW & ACT?

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Answered: 152 Skipped: 1



## Q4: Are you a member of Huntington's NSW & ACT?

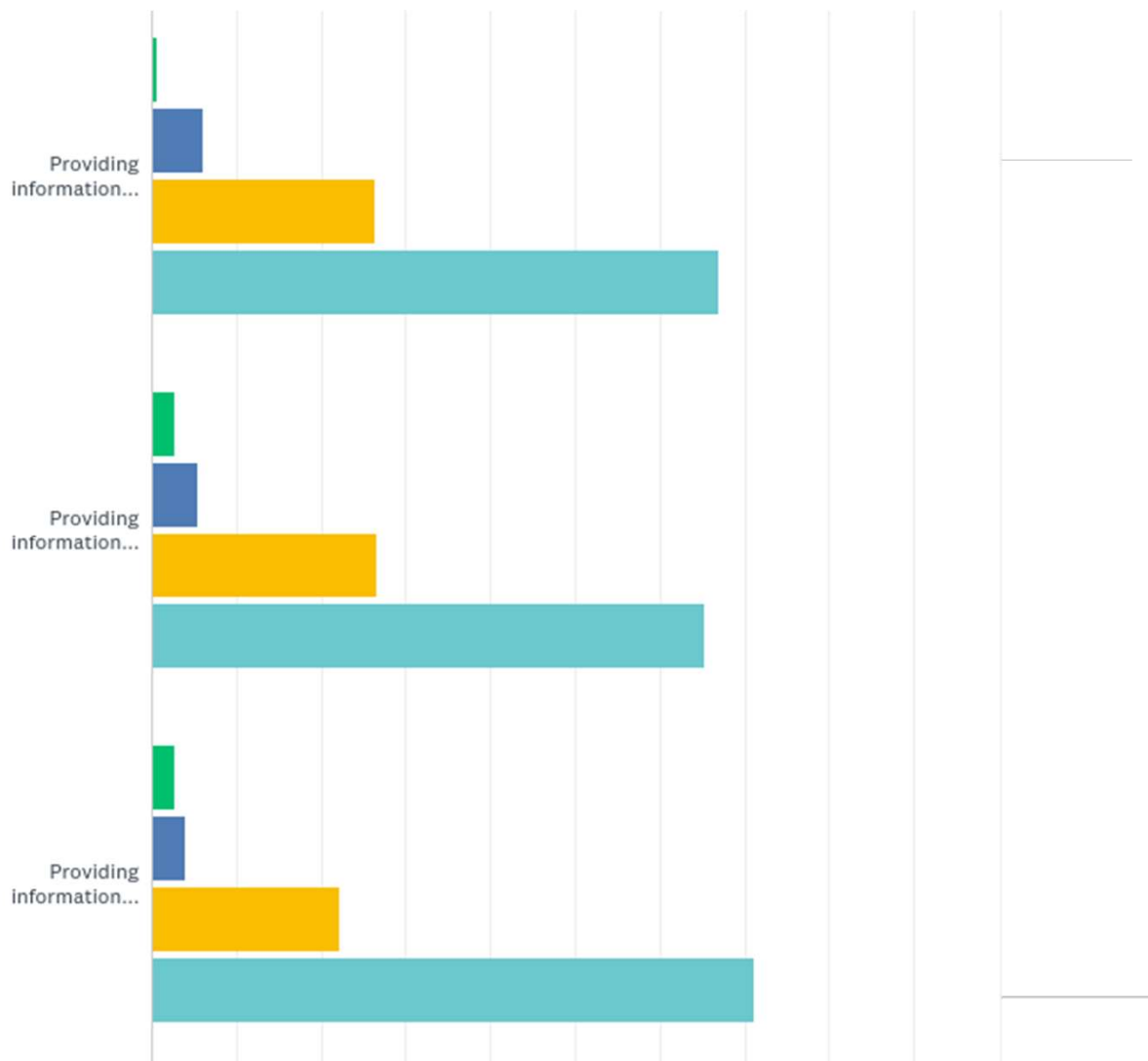
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Answered: 152 Skipped: 1

ANSWER CHOICES	RESPONSES	
Yes	72.37%	110
No	27.63%	42
TOTAL		152

# Q5: For each of these supp please indicate its importan

Answered: 152 Skipped: 1



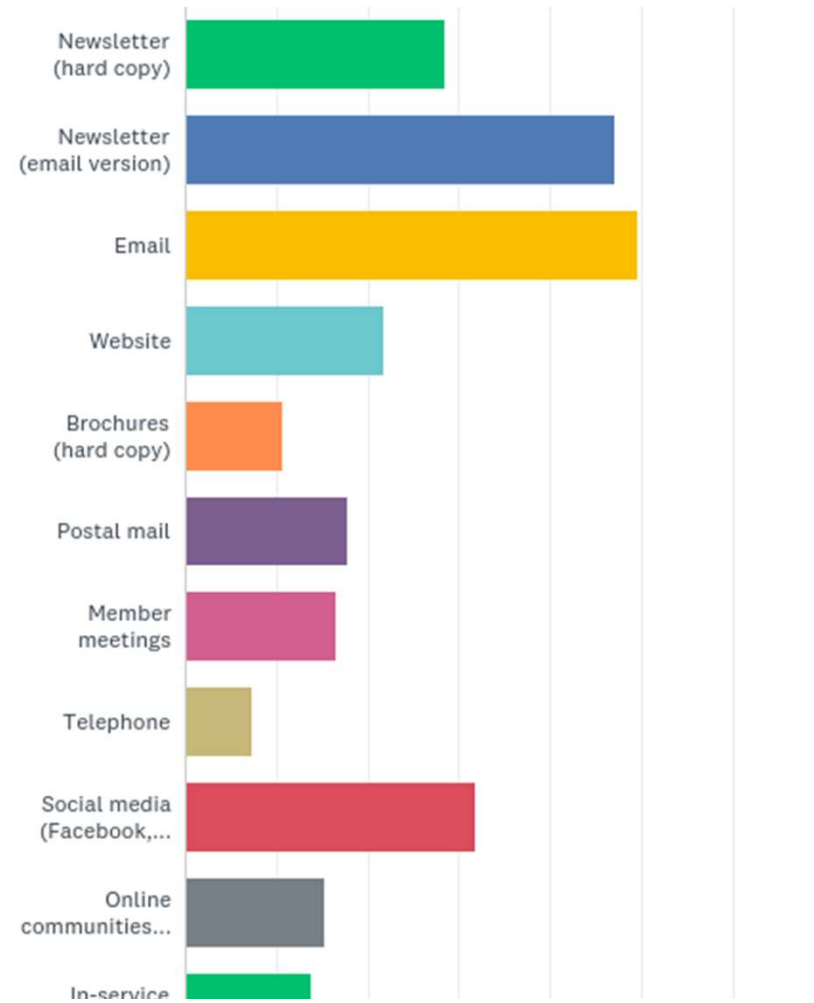
## Q5: For each of these please indicate its importance

Answered: 152 Skipped: 1

	NOT IMPORTANT	SLIGHTLY IMPORTANT	MODERATELY IMPORTANT	VERY IMPORTANT		AVERAGE
Providing information about HD	0.68% 1	6.08% 9	26.35% 39	66.89% 99	148	3.59
Providing information about caring for someone with HD	2.72% 4	5.44% 8	26.53% 39	65.31% 96	147	3.54
Providing information about accessing health services for HD	2.68% 4	4.03% 6	22.15% 33	71.14% 106	149	3.62
Educating health care professionals about HD	2.67% 4	2.67% 4	26.67% 40	68.00% 102	150	3.60
Running social (lunch) clubs	17.93% 26	27.59% 40	33.79% 49	20.69% 30	145	2.57
Running an annual holiday camp	24.66% 36	26.71% 39	34.25% 50	14.38% 21	146	2.38
Providing support for young people	6.76% 10	10.14% 15	27.70% 41	55.41% 82	148	3.32
Providing...	5.56%	7.64%	31.25%	55.56%		

## Q6: How would you like Huntington's NSW & ACT to communicate with you? (Tick more than one box if you want.)

Answered: 151 Skipped: 2



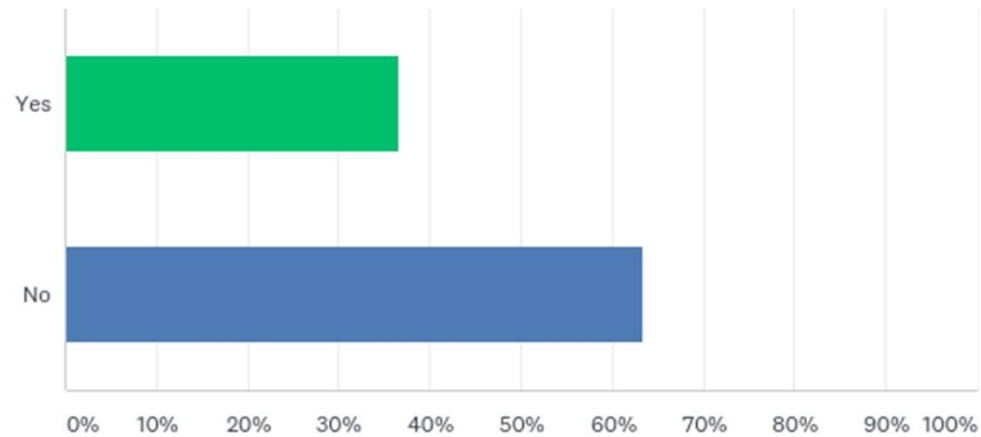
## Q6: How would you like Huntington's NSW & ACT to communicate with you? (Tick more than one box if you want.)

Answered: 151 Skipped: 2

ANSWER CHOICES	RESPONSES	
Newsletter (hard copy)	28.48%	43
Newsletter (email version)	47.02%	71
Email	49.67%	75
Website	21.85%	33
Brochures (hard copy)	10.60%	16
Postal mail	17.88%	27
Member meetings	16.56%	25
Telephone	7.28%	11
Social media (Facebook, Twitter)	31.79%	48
Online communities (private member online community network)	15.23%	23
In-service (home visit)	13.91%	21
Other (please specify)	3.97%	6
Total Respondents: 151		

**Q7. Are you or a family member using National Disability Insurance Scheme (NDIS) services? (NOTE: Huntington's NSW & ACT is setting up an NDIS coordination of support service.)**

Answered: 153 Skipped: 0



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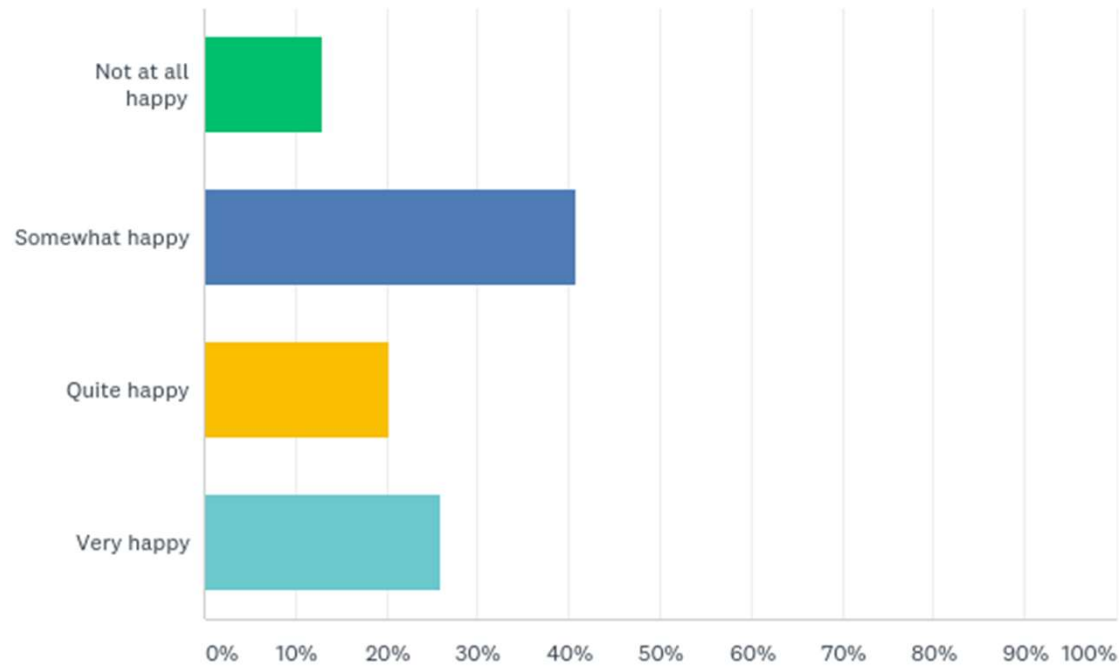
Answered: 153 Skipped: 0

ANSWER CHOICES	RESPONSES	
Yes	36.60%	56
No	63.40%	97
TOTAL		153



## Q8: ONLY if you answered yes to Q. 7: Are you happy with the NDIS services you or your family member receive?

Answered: 54 Skipped: 99



## Q8: ONLY if you answered yes to Q. 7: Are you happy with the NDIS services you or your family member receive?

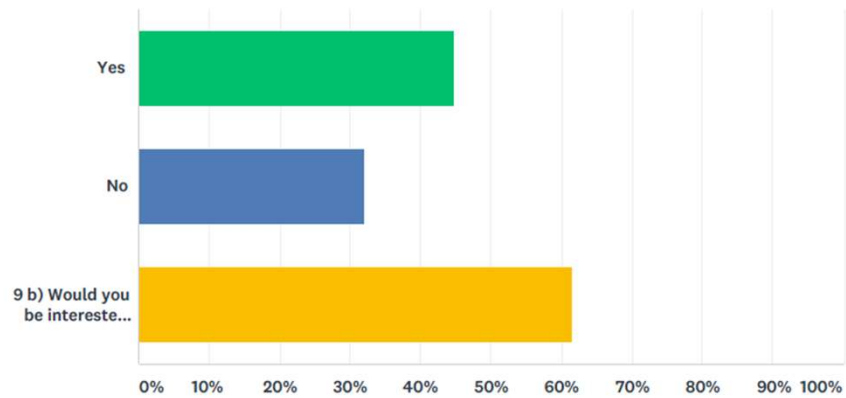
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Answered: 54 Skipped: 99

ANSWER CHOICES	RESPONSES	
Not at all happy	12.96%	7
Somewhat happy	40.74%	22
Quite happy	20.37%	11
Very happy	25.93%	14
TOTAL		54

Q9 ONLY if you answered yes to Q. 8 Are you using or have you used NDIS coordination of support?

Answered: 78 Skipped: 75



ANSWER CHOICES	RESPONSES
Yes	44.87% 35
No	32.05% 25
9 b) Would you be interested in learning about Huntington's NSW & ACT NDIS coordination of support service? Please tick the box if yes.	61.54% 48
Total Respondents: 78	