

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.

09 March, 2020

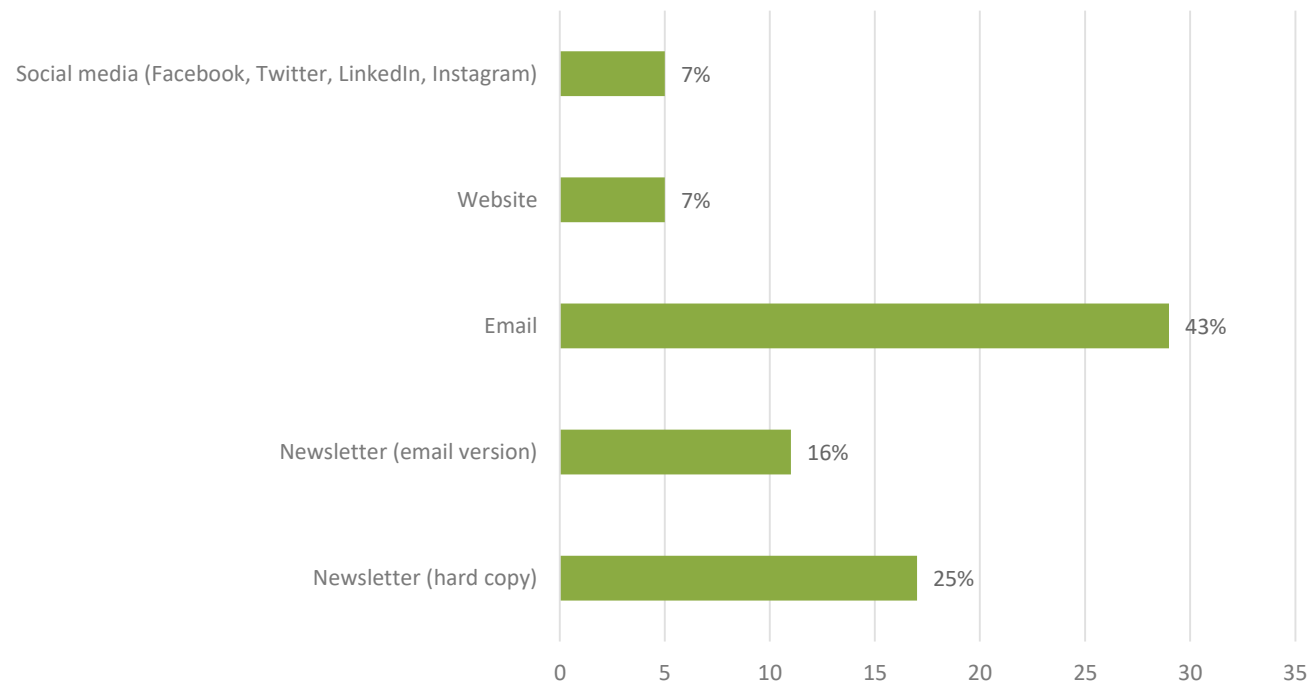
64
Total Responses

Date Created: 09 March, 2020

Complete Responses: 64

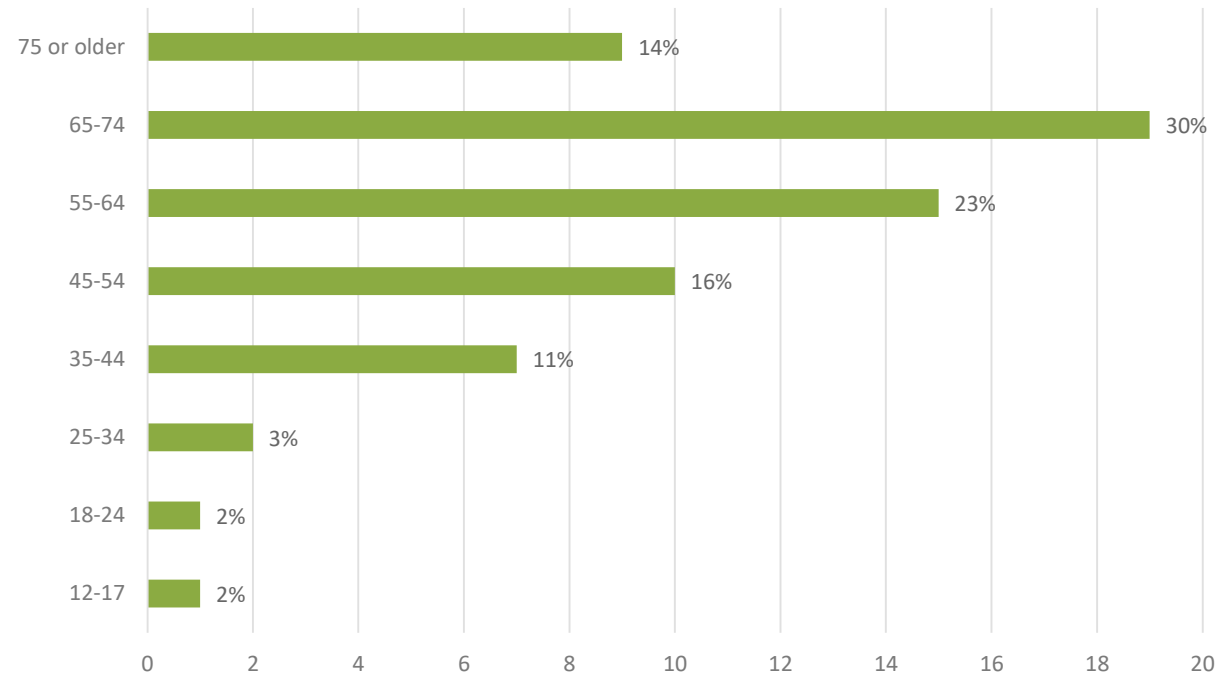
Q1: How did you access this survey?

Answered: 67 Skipped: 0



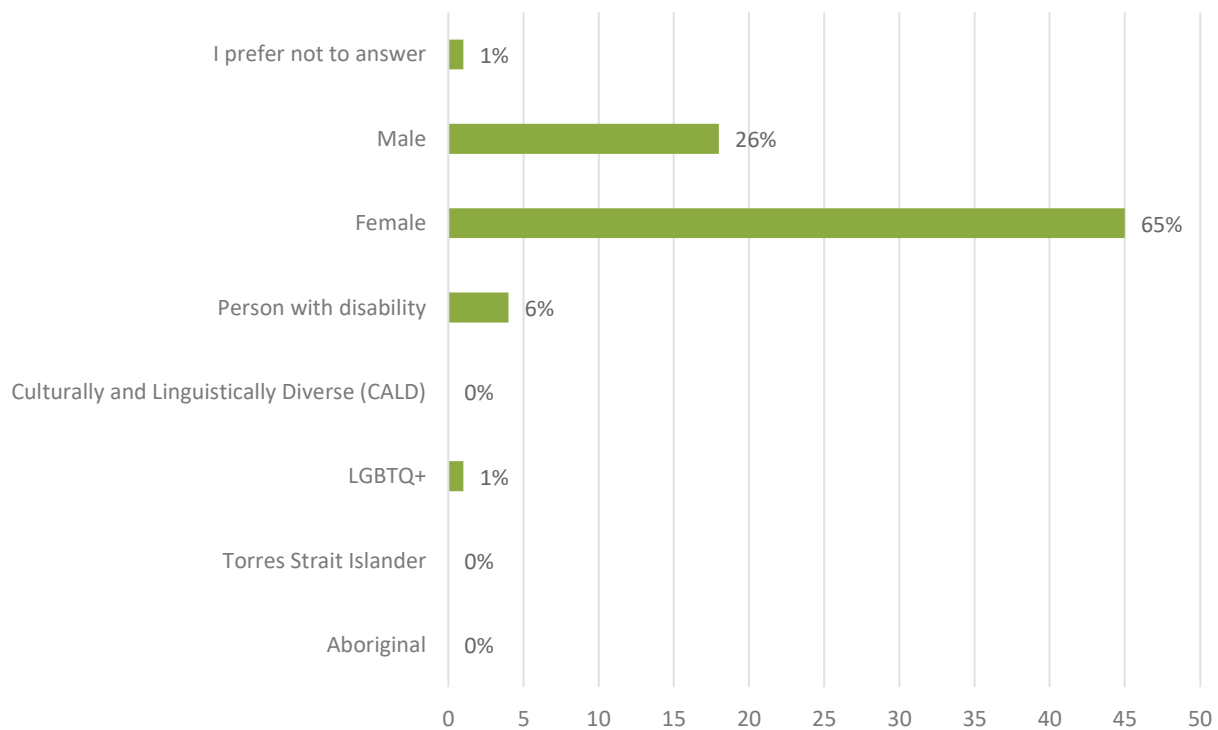
Q2: What is your age range and postcode?

Answered: 64 Skipped: 0



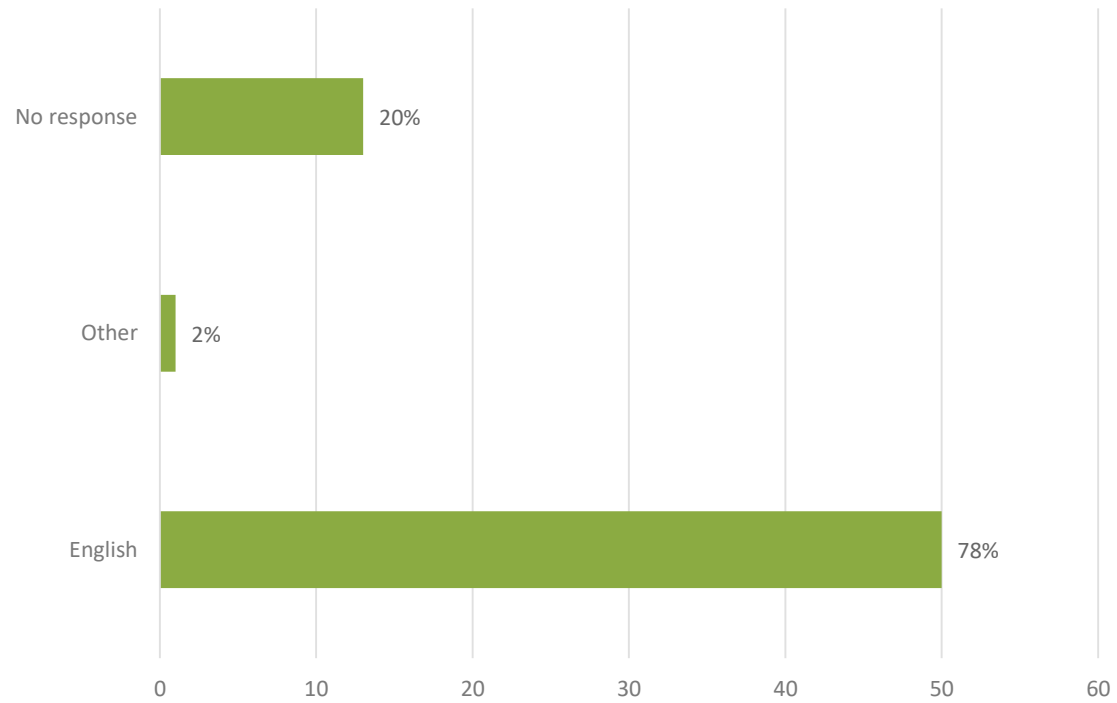
Q3a: Please select any / all option/s that you best identify with: (You can tick more than one box.)

Answered: 69 Skipped: 0



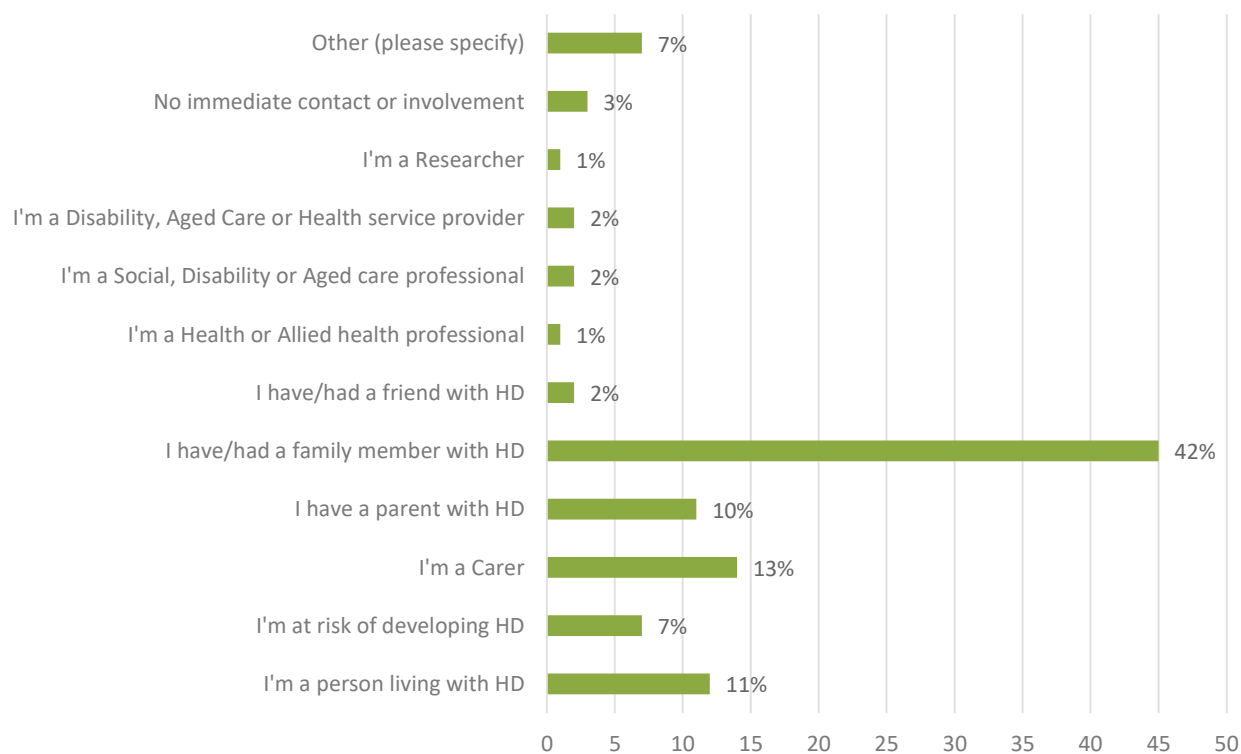
Q3b: What language do you speak in your home?

Answered: 61 Skipped: 13



Q4: What is your relationship to Huntington's disease? (You can tick more than one box.)

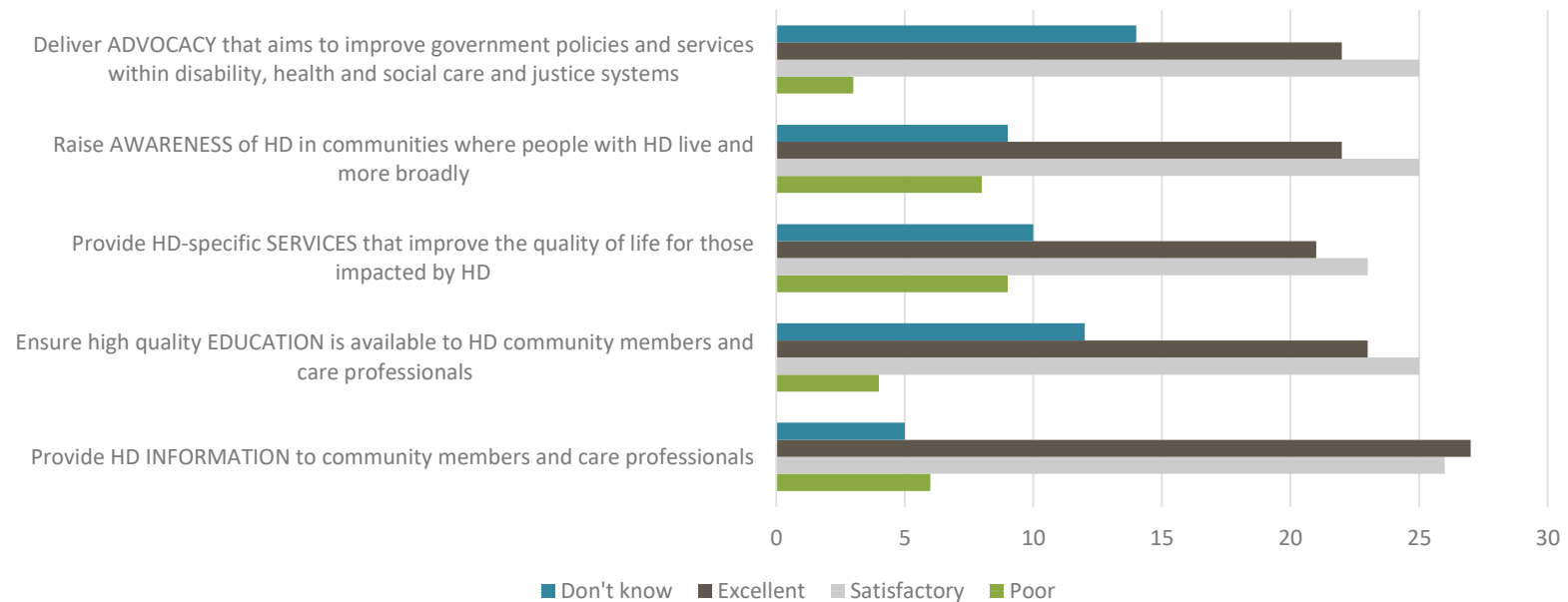
Answered: 107 Skipped: 0



Q5: How would you rate us against our goals for NSW and ACT

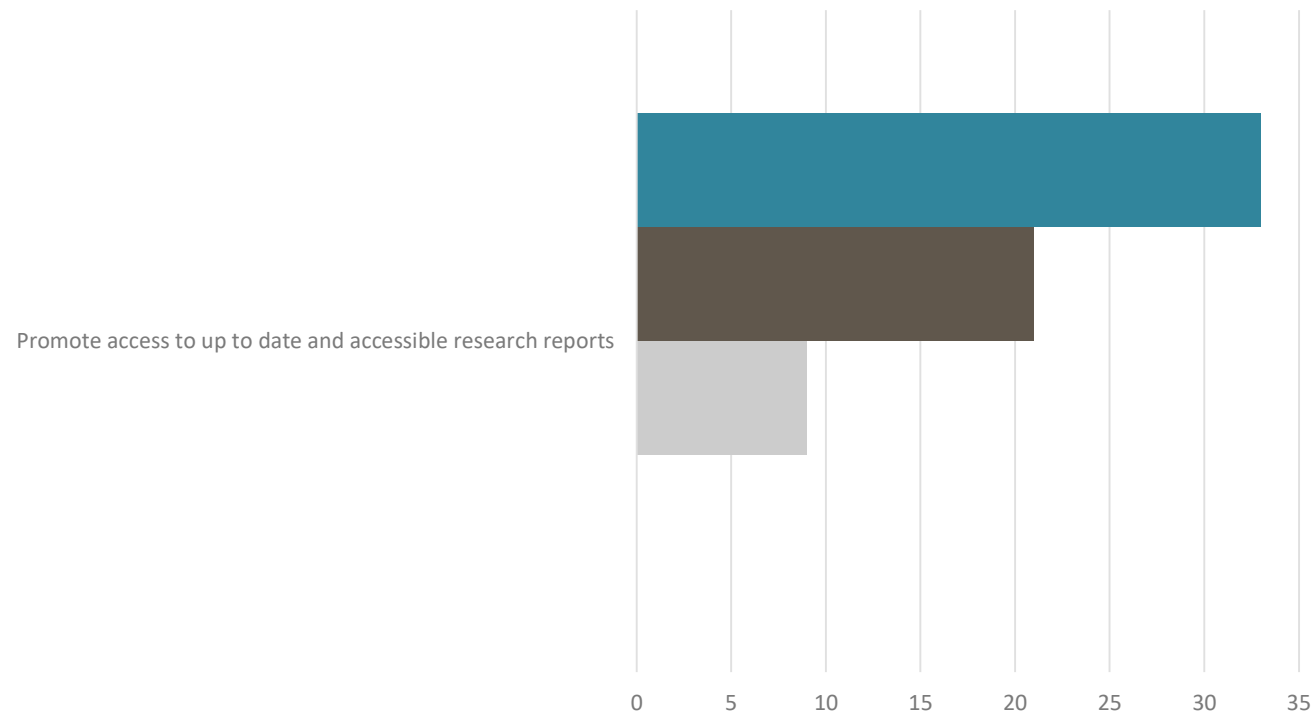
Answered: 319 Skipped: 1

Rating of Strategic plan: goals



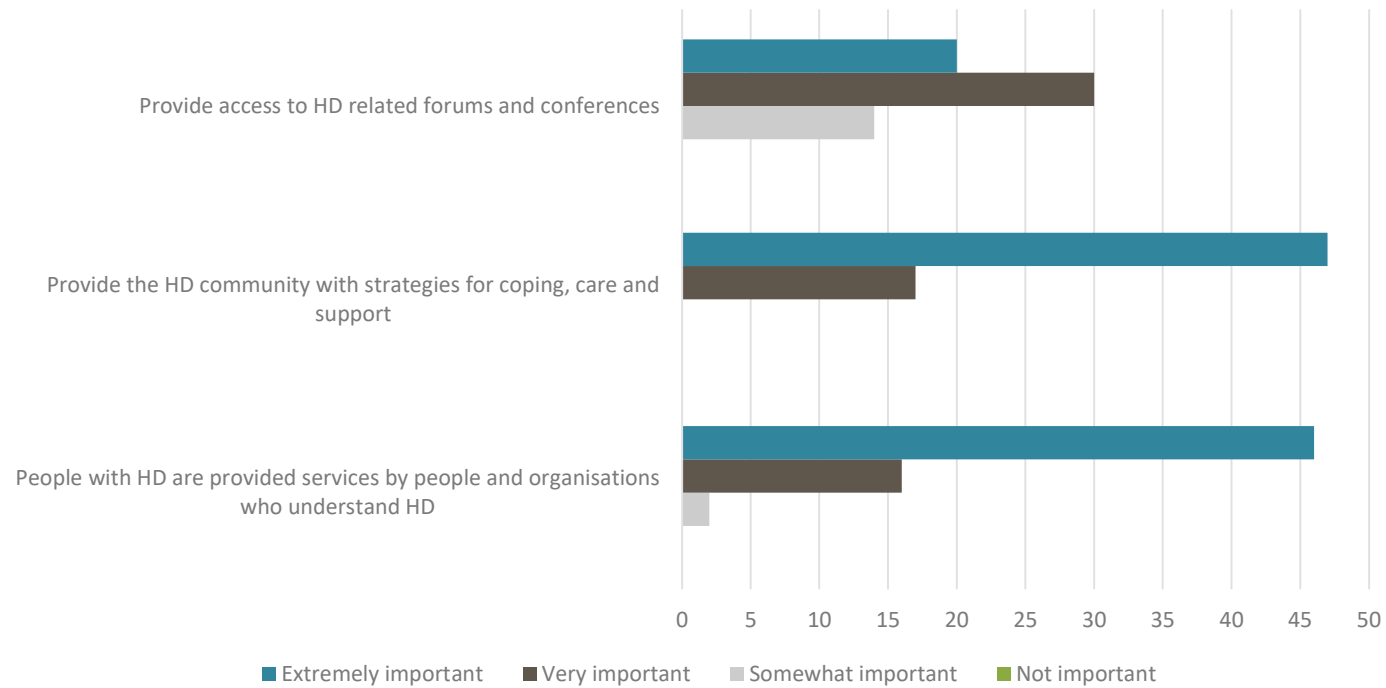
Q6: Goal 1: Be the peak organisation providing HD INFORMATION to community members and care professionals within NSW and ACT

Answered: 64 Skipped: 0



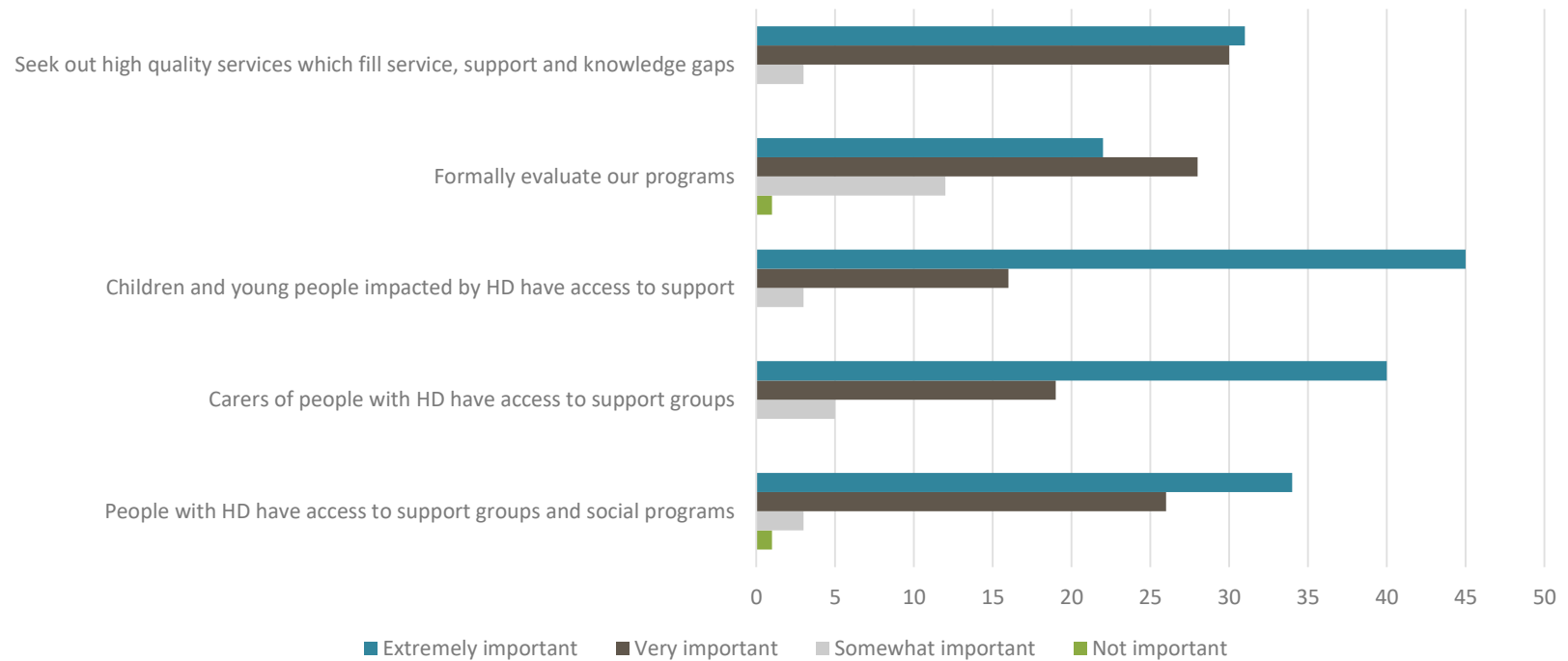
Q6: Goal 2: Ensure high quality EDUCATION is available to HD community members and care professionals within NSW and ACT

Answered: 63 Skipped: 1



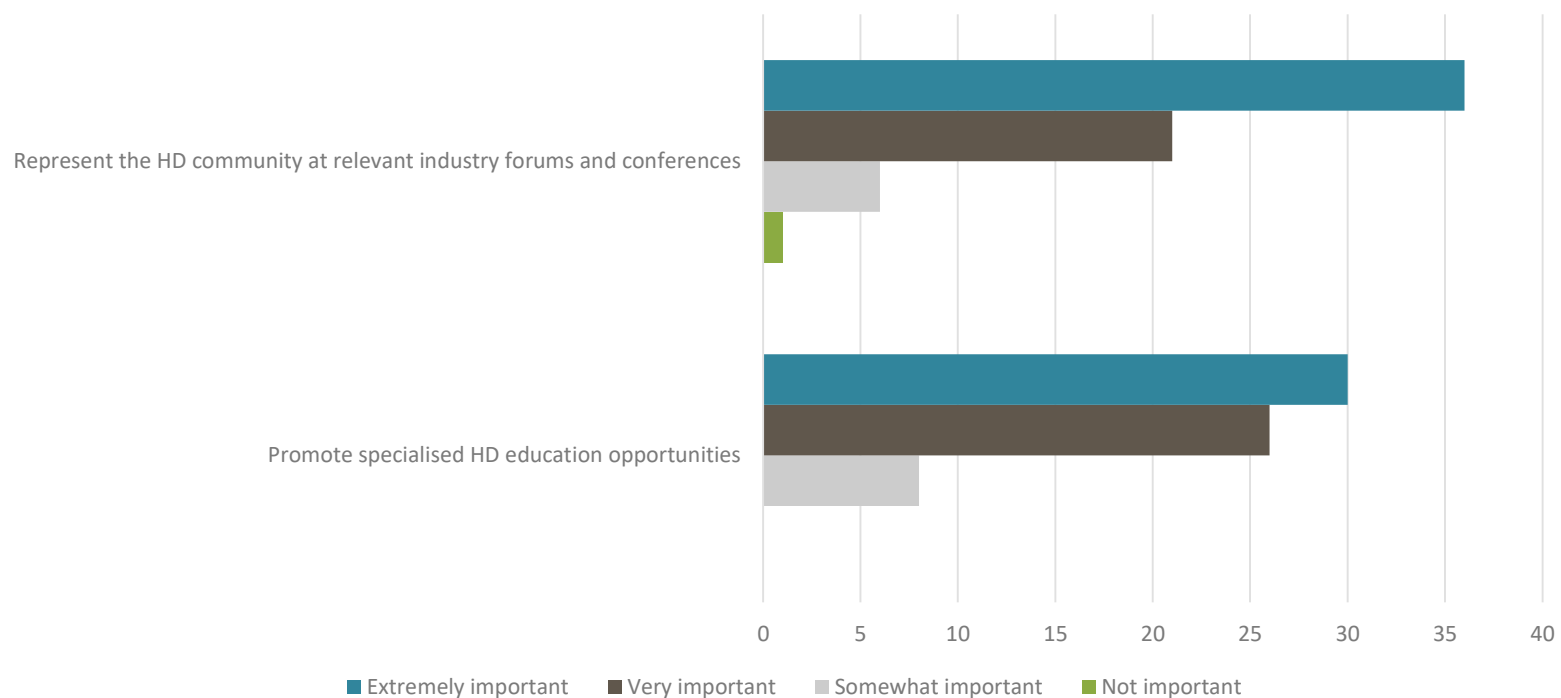
Q6: Goal 3: Provide HD-specific SERVICES that improve the quality of life for those impacted by HD

Answered: 64 Skipped: 0



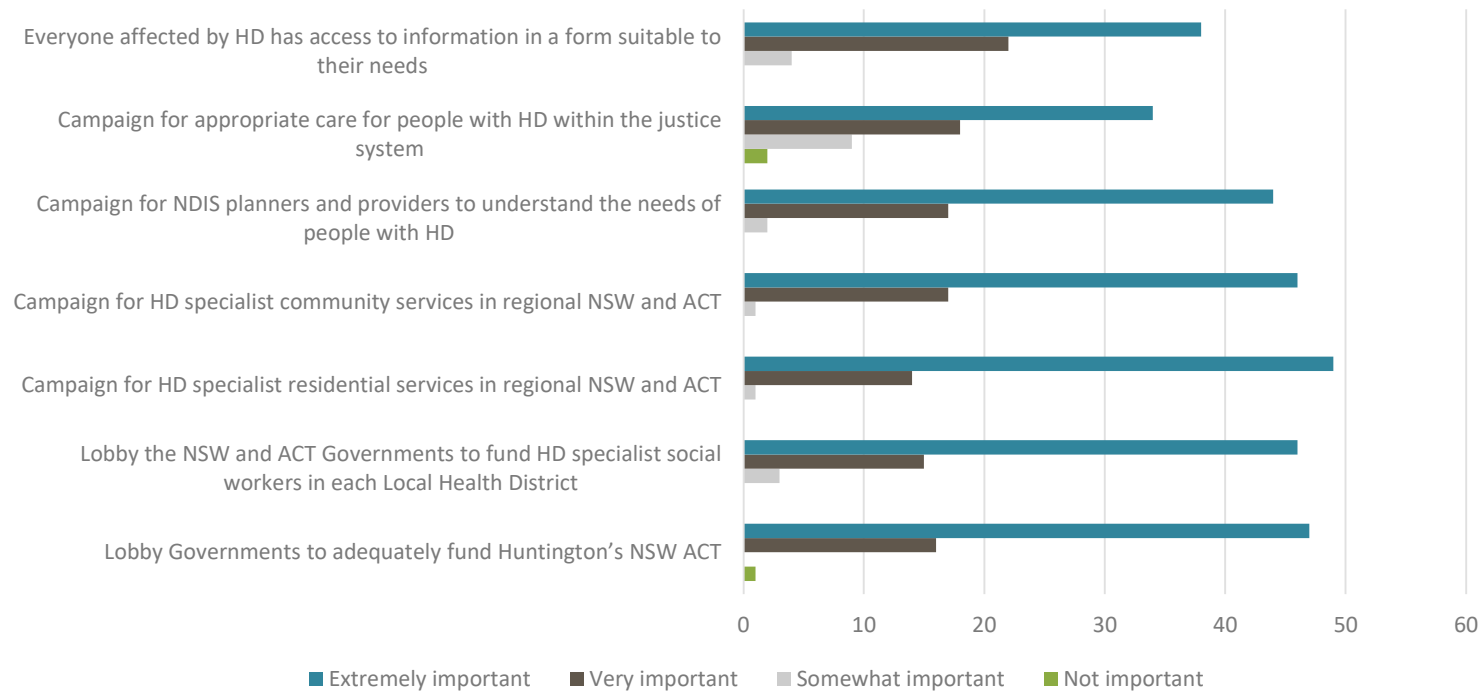
Q6: Goal 4: Raise AWARENESS of HD in communities where people with HD live and more broadly

Answered: 64 Skipped: 0



Q6. Goal 5: Respond to the concerns and aspirations of our members through **ADVOCACY** that aims to improve government policies and services within disability, health and social care and justice systems

Answered: 64 Skipped: 0

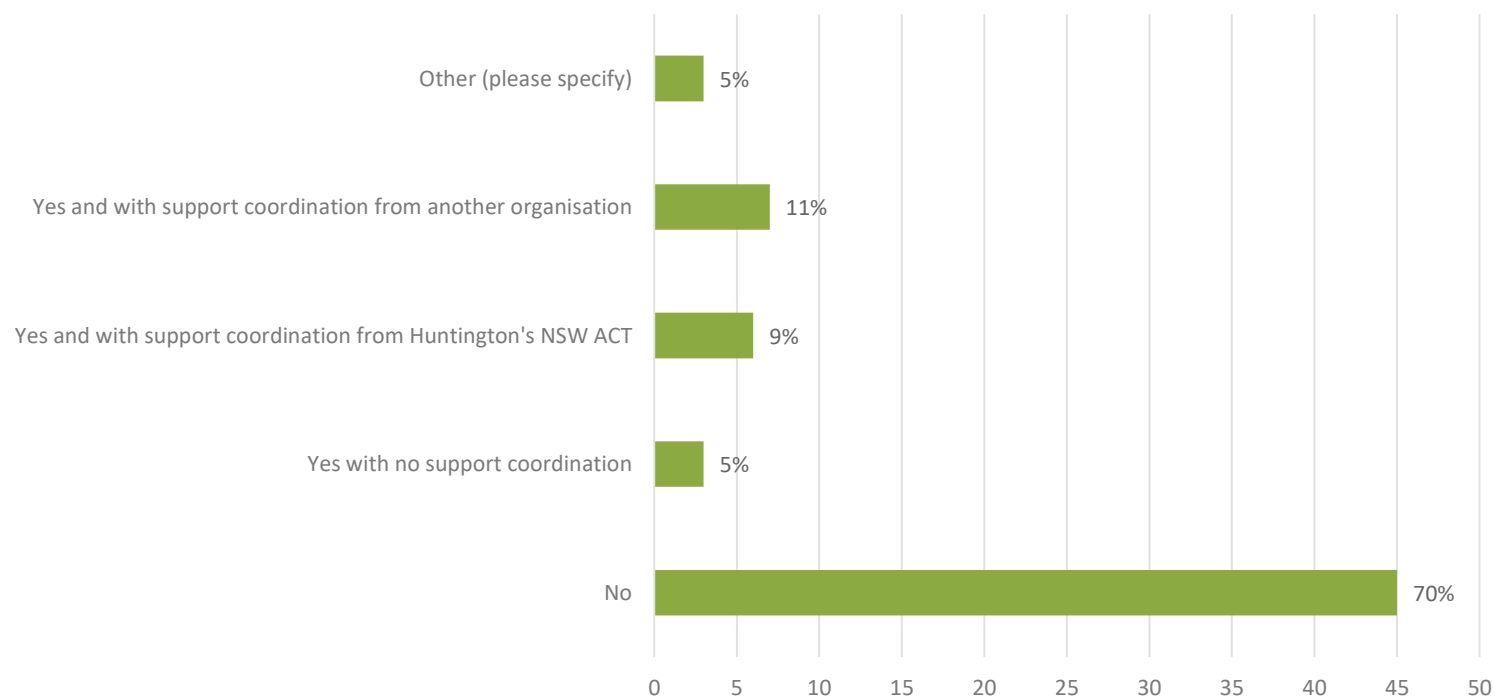


Q6: Goal ranking

	Ranking
Provide the HD community with strategies for coping, care and support	1
Lobby Governments to adequately fund Huntington's NSW ACT	2
Campaign for HD specialist residential services in regional NSW and ACT	2
Campaign for HD specialist community services in regional NSW and ACT	2
People with HD are provided services by people and organisations who understand HD	3
Campaign for NDIS planners and providers to understand the needs of people with HD	4
Children and young people impacted by HD have access to support	5
Seek out high quality services which fill service, support and knowledge gaps	5
Lobby the NSW and ACT Governments to fund HD specialist social workers in each Local Health District	5
People with HD have access to support groups and social programs	6
Everyone affected by HD has access to information in a form suitable to their needs	6
Carers of people with HD have access to support groups	7
Represent the HD community at relevant industry forums and conferences	8
Promote specialised HD education opportunities	9
Promote access to up to date and accessible research reports	10
Campaign for appropriate care for people with HD within the justice system	11
Formally evaluate our programs	12
Provide access to HD related forums and conferences	13

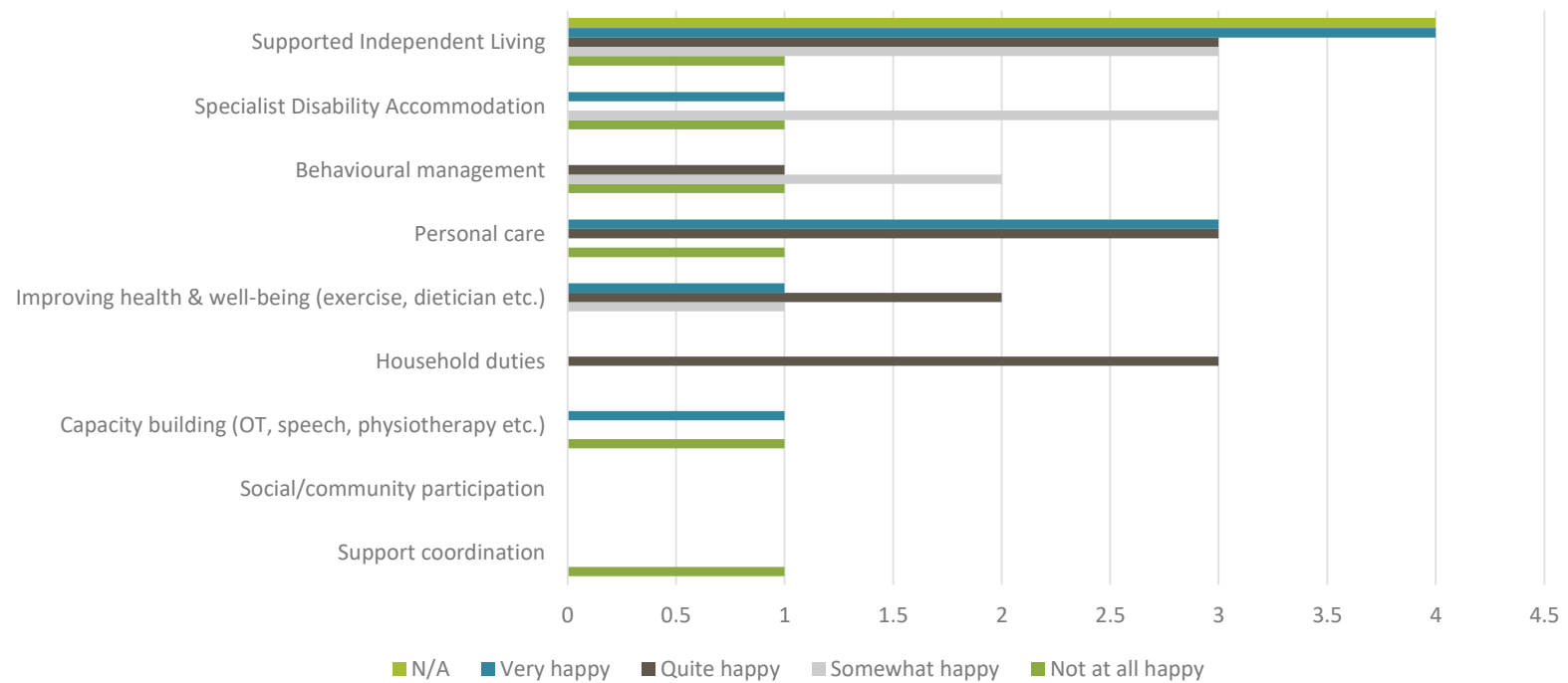
Q7: Is there a person with HD in your household who is an NDIS participant?

Answered: 64 Skipped: 0



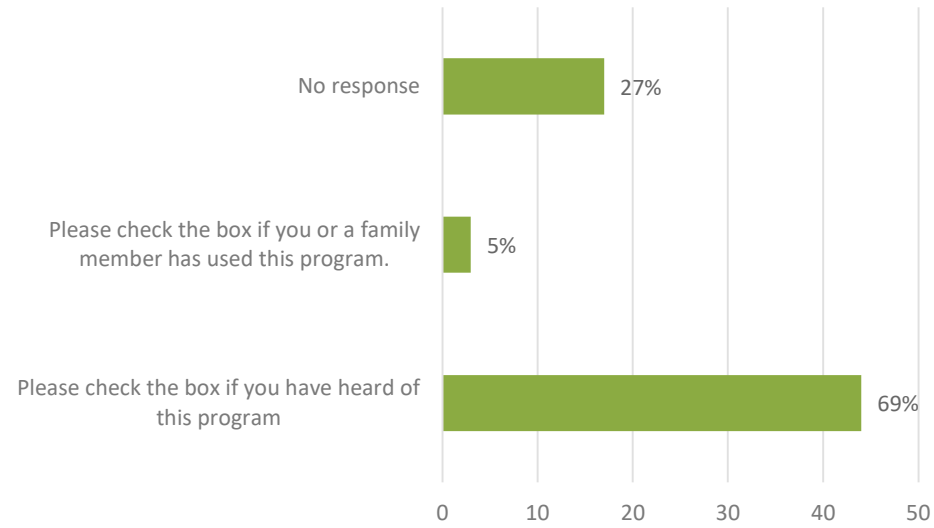
Q7b: ONLY if you answered yes to Q. 7: How happy are you with the NDIS services received for:(leave section blank if not receiving that service type)

Answered: 41 Skipped: 0



Q8: HD Youth Connection Program

Answered: 47 Skipped: 17



Q9: We are planning to establish an online HD education program for families and providers. Please rate the importance to you and your family of the issues below.

Answered: 384 Skipped: 0

