



Lived
Experience
AUSTRALIA

Inquiry into the Equity, Accessibility and Appropriate Delivery of Outpatient and Community Mental Health Care in NSW

5th September 2023

Submitted to:

Parliament of New South Wales
Legislative Council
Portfolio Committee 2-Health

Council Contact:

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Introduction

Lived Experience Australia Ltd (LEA) is a national representative organisation for Australian mental health consumers and carers, families and kin, formed in 2002 with a focus on the private sector. All members of our Board and staff have mental health lived experience as either a consumer, family carer or both. This is core to our advocacy, recognising that the impacts of policy and practice are felt not only by individuals, but also by families and whole communities.

Our core business is to advocate for systemic change to improve mental health care (including psychosocial disability) across the whole Australian health system, including within NSW and all other State and Territory jurisdictions. This includes advocating for empowerment of people with mental health lived experience (people with mental health conditions and their family, carers and kin) in the broad range of issues that impact their mental and physical health, and their lives more broadly. It includes empowering them in their own care and contact with health and social services, promoting their engagement and inclusion within system design, planning and evaluation and most importantly, advocating for systems that promote choice, inclusion, justice and fairness, and address abuse, violence, exploitation, neglect, stigma, discrimination and prejudice.

Our feedback to the Portfolio Committee (No.2 – Health) established by the NSW Legislative Council into the delivery of outpatient and community mental health care in NSW comes from the perspectives and experiences of consumers with mental health lived experience, and from the perspectives of their families, carers and supporters.

(In addition to this submission, we have provided lived experience expertise to the Australian Private Hospital Association (APHA) submission to this inquiry. Our Chair and Executive Director is the lived experience representative for private sector consumers and carers on the APHA Psychiatric Committee, and we urge you to also consider the issues raised in that submission.)

Purpose of this Inquiry

That Portfolio Committee inquire into and report on:

- (a) equity of access to outpatient mental health services
- (b) navigation of outpatient and community mental health services from the perspectives of patients and carers
- (c) capacity of State and other community mental health services, including in rural, regional and remote New South Wales
- (d) integration between physical and mental health services, and between mental health services and providers
- (e) appropriate and efficient allocation of mental health care workers, including psychiatrists, nurses, psychologists, GPs, councillors, social workers, allied health professionals and peer workers
- (f) the use of Community Treatment Orders under the Mental Health Act 2007
- (g) benefits and risks of online and telehealth services
- (h) accessibility and cultural safety of mental health services for First Nations people, culturally and linguistically diverse (CALD), LGBTQIA+ people, young people, and people with disability

(i) alternatives to police for emergency responses to people experiencing acute mental distress, psychosis, delirium, dementia or intoxication in the community, including but not limited to Police, Ambulance, Clinical, Early, Response (PACER)

(j) any other related matter.

Our Response

We provide findings drawn from two recent national projects where we sought the lived experiences of mental health consumers and carers across Australia. For this submission, we have provided NSW-specific findings as they relate to the areas of focus for this current inquiry.

1. The first project (**the Missing Middle Report**) explored experiences of disengagement from mental health services and what people said would help them to re-engage with services.

The full report can be found here:

- Kaine, C. & Lawn, S. (2021) The 'Missing Middle' Lived Experience Perspectives. Lived Experience Australia Ltd: Marden, South Australia, Australia. ISBN: 978-0-6450753-0-4 <https://www.livedexperienceaustralia.com.au/missingmiddlemedia>
- Kaine, C. & Lawn, S. (2021) The 'Missing Middle' Our Voices. Lived Experience Australia Ltd: Marden, South Australia, Australia. ISBN: 978-0-6450753-2-8 <https://www.livedexperienceaustralia.com.au/missingmiddlemedia>

NSW-specific Missing Middle Data:

63 consumers and 23 family/carers from NSW completed this survey.

Consumers were asked to rate the primary reason why they used particular mental healthcare providers as their primary source of support. Major contributing reasons were:

- They listen to me (53%)
- I can afford to pay for this service (48%)
- They include/collaborate with me (45%)

When asked if they were able to access a mental health service or a health professional in a reasonable time, 50% said 'No'.

Once they received support, 46% said the health professional or service did not help them for the length of time that they felt they needed. This experience was similar for carers (44%)

83% of consumers and 94% of family/carers said that disengagement from mental health services is an issue for a lot of people.

When asked whether the health professional or service gave them or their family/carer sufficient notice of impending discharge from the service, 27% said 'Yes', 41% said 'No', and 32% were unsure. Carer perspectives were similar.

Consumers were asked to rate the primary reason why they decided not to engage with or continue with health professionals or services. Major contributing reasons were:

- The service didn't meet my needs (45%)
- Lack of plan/goals/didn't seem to be progressing/going anywhere (44%)
- Worker changed frequently/no consistent worker (43%)
- The service didn't offer me the right type of support that I needed (42%)

Major contributing reasons reported by family/carers were:

- The service didn't offer the person the right type of support that they needed (43%)
- Limited options/choice of service providers in their area (38%)

Consumers were asked to rate the primary reason (from a PERSONAL perspective) why they decided not to engage with or continue with health professionals or services. Major contributing reasons were:

- They didn't listen to me (56%)
- They didn't include/collaborate with me (51%)
- I felt I had little say or control in making decisions (50%)
- I felt judged/stigmatised (49%)

Major contributing reasons reported by family/carers about the experiences of the person they support were:

- They didn't include/collaborate with the person (36%)
- They felt they had little say or control in making decisions (36%)
- They felt judged/stigmatised (36%)

When asked about their experiences of communication and collaboration between health professionals and/or services, 66% of consumers said there was 'No Coordination', 50% of consumers didn't have a consistent person they could contact or speak to, 47% felt that they 'fell through the cracks', and 47% had to retell their story each time they contacted for help.

Carer experiences were similar: 58% of family/carers said there was 'No Coordination', 67% said there was 'No referral to other services', 58% said the person was 'discharged with no other option', and 50% said they 'didn't have a consistent person they could contact or speak to'.

If they found themselves in a crisis, consumers said the following had contributed to the deterioration in their condition:

- Couldn't access support when needed (69%)
- Not connected to existing services (45%)
- Regular health professional not available (37%)

Carers held similar views about the contributing factors for the person they support:

- Couldn't access support when needed (69%)
- Regular health professional not available (62%)

(See Appendix A for details more information, including tables and graphs)

2. The second project (**the Review of Physical and Mental Health Care Report**) explored experiences of health professionals' attention to physical health concerns for people with mental health conditions, from the consumer and carer perspective.

The full report can be found here:

- Kaine, C., Lawn, S., Roberts, R., Cobb, L., & Erskine, V. (2022) Review of Physical and Mental Health Care in Australia, Lived Experience Australia Ltd: Marden, South Australia, Australia. <https://www.livedexperienceaustralia.com.au/research>

NSW-specific Mental Health and Physical Health data:

44 consumers from NSW responded to this survey. General Practitioners (GPs) are the main provider of physical and mental health care for consumers.

Consumers said that a GP had asked them about a range of physical health concerns in the past 12 months, predominantly about healthy eating, vaccinations, blood pressures, exercise and physical activity, sleep, weight, and blood tests. However:

- Approx. two thirds of consumers who smoked were not asked about their smoking
- More than half who had alcohol and drug use were not asked about this
- Most were not asked about their sexual health
- Approx. half were not asked about cholesterol, diabetes, weight, sleep, cancer screening
- Almost half were not asked about side effects of medications

Whilst 51% had been asked about exercise and physical activity, and 57% had been asked about sleep, a higher proportion of consumers said that a mental health professional (other than a GP) had not asked them about a range of physical health concerns in the past 12 months:

- 86% of consumers who smoked were not asked about their smoking
- 62% who had alcohol and drug use were not asked about this
- 76% were not asked about their sexual health
- 94% were not asked about their cholesterol
- 90% were not asked about diabetes
- 91% were not asked about their blood pressure
- 76% were not asked about weight
- 67% were not asked about side effects of medications

Consumers were asked more information about their experiences with mental health professionals in relation to their physical health:

- Half said their mental health professional never or rarely routinely ask about their physical health.
- Almost half said their mental health professional often or always takes seriously any concerns that the consumer raises about their physical health (i.e. the consumer must raise the concern first) and they are interested in their whole health, not just their mental health.
- Approximately 32% said mental health professionals never or rarely listen to their concerns about medications.
- Approximately 38% said their mental health professional never or rarely provided them with clear information about tests, medications or concerns in a way that they could understand.
- Approximately 42% said their mental health professional never or rarely keeps them informed and includes them in each step and decision about their physical health care.
- Approximately 35% said they never or rarely have enough access to allied health professionals to support their physical health.
- Almost half (47%) said that, when they needed to go to hospital or an emergency department for their mental health, health professionals had never or rarely asked about their physical health.

(See Appendix B for more detailed information, including tables and graphs)

Contact

We thank the Portfolio Committee for the opportunity to provide the enclosed perspectives from a sample of NSW consumers and carers on their experiences of community mental health care. We wish you well with the next steps and would be keen to contribute our lived experience perspectives to any future discussions about this important topic.

Your sincerely

Sharon Lawn

Professor Sharon Lawn
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Appendix A: NSW Data - Missing Middle Report

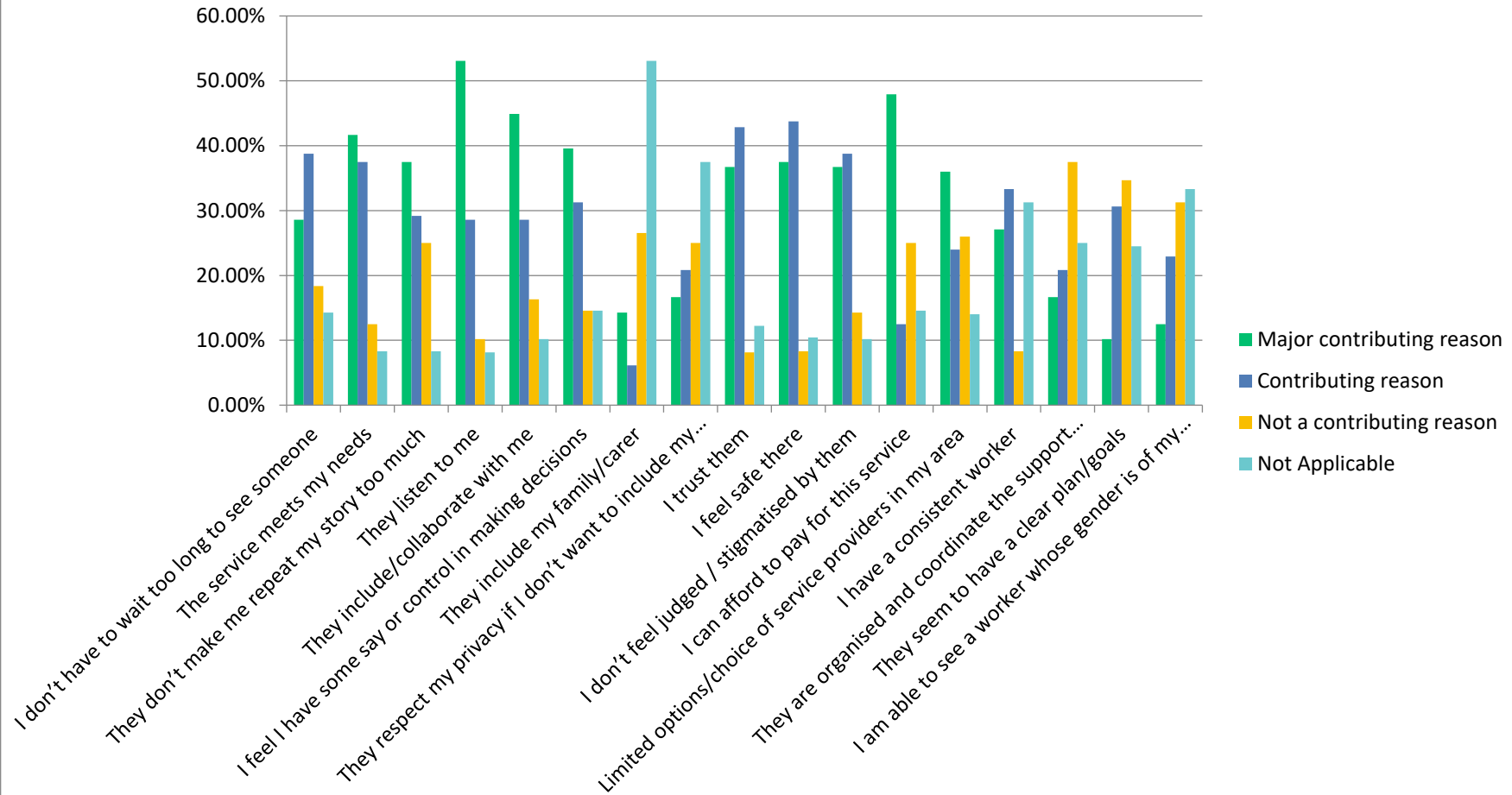
Please explain the main reasons why you use this as your primary source of mental health support? Rate each of the following reasons

	Major contributing reason		Contributing reason		Not a contributing reason		Not Applicable		Total
I don't have to wait too long to see someone	28.57%	14	38.78%	19	18.37%	9	14.29%	7	49
The service meets my needs	41.67%	20	37.50%	18	12.50%	6	8.33%	4	48
They don't make me repeat my story too much	37.50%	18	29.17%	14	25.00%	12	8.33%	4	48
They listen to me	53.06%	26	28.57%	14	10.20%	5	8.16%	4	49
They include/collaborate with me	44.90%	22	28.57%	14	16.33%	8	10.20%	5	49
I feel I have some say or control in making decisions	39.58%	19	31.25%	15	14.58%	7	14.58%	7	48
They include my family/carer	14.29%	7	6.12%	3	26.53%	13	53.06%	26	49
They respect my privacy if I don't want to include my family	16.67%	8	20.83%	10	25.00%	12	37.50%	18	48
I trust them	36.73%	18	42.86%	21	8.16%	4	12.24%	6	49
I feel safe there	37.50%	18	43.75%	21	8.33%	4	10.42%	5	48
I don't feel judged / stigmatised by them	36.73%	18	38.78%	19	14.29%	7	10.20%	5	49
I can afford to pay for this service	47.92%	23	12.50%	6	25.00%	12	14.58%	7	48
Limited options/choice of service providers in my area	36.00%	18	24.00%	12	26.00%	13	14.00%	7	50
I have a consistent worker	27.08%	13	33.33%	16	8.33%	4	31.25%	15	48
They are organised and coordinate the support services I need	16.67%	8	20.83%	10	37.50%	18	25.00%	12	48
They seem to have a clear plan/goals	10.20%	5	30.61%	15	34.69%	17	24.49%	12	49
I am able to see a worker whose gender is of my choosing	12.50%	6	22.92%	11	31.25%	15	33.33%	16	48
Other (please specify)									

19

Answered 51

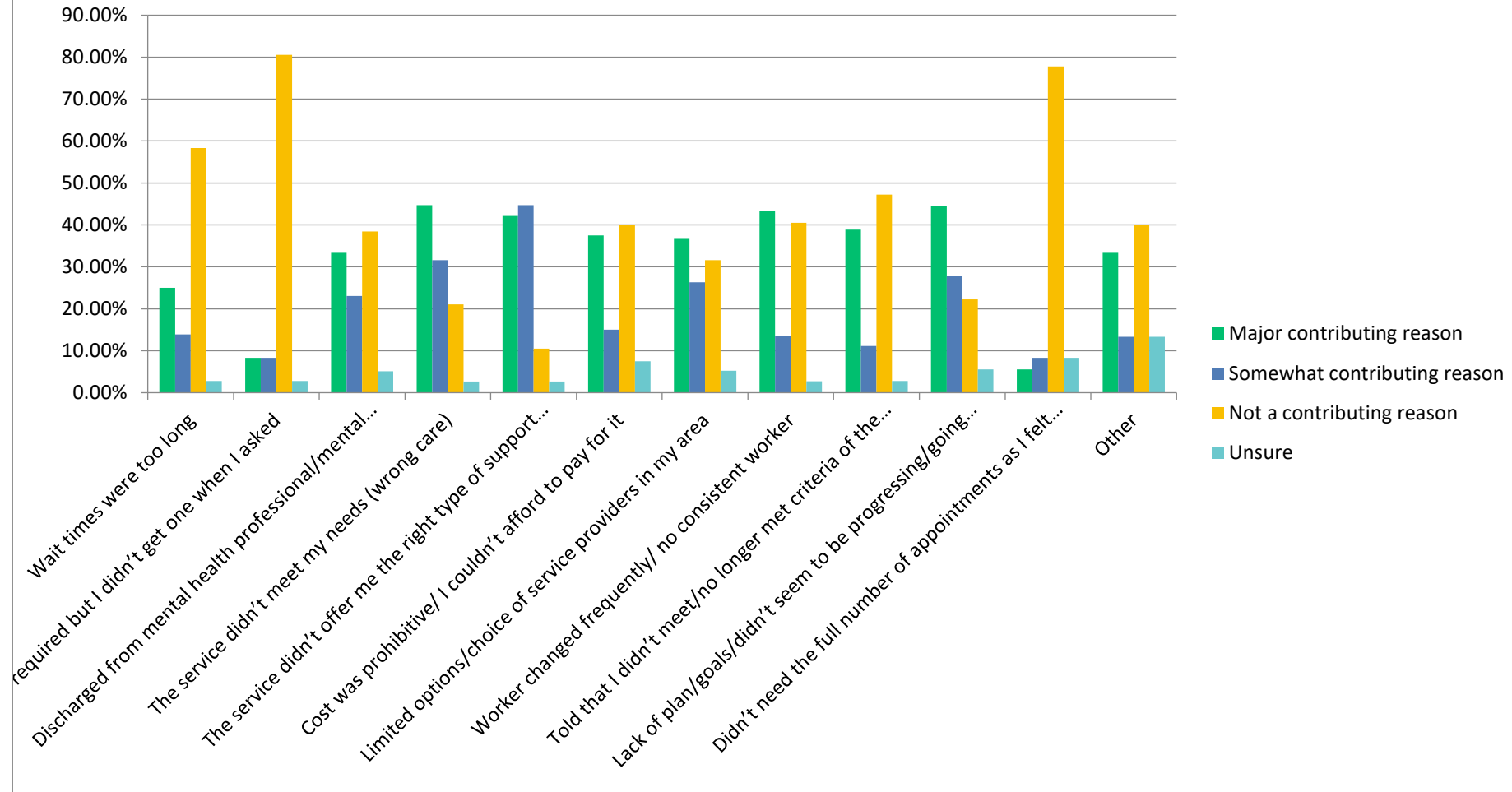
Please explain the main reasons why you use this as your primary source of mental health support? Rate each of the following reasons



Thinking about the health professional or service that you decided not to engage with (continue with) in the past, what was the primary reason you decided to stop (disengage)?

	Major contributing reason		Somewhat contributing reason		Not a contributing reason		Unsure	Total	
Wait times were too long	25.00%	9	13.89%	5	58.33%	21	2.78%	1	36
A referral was required but I didn't get one when I asked	8.33%	3	8.33%	3	80.56%	29	2.78%	1	36
Discharged from mental health professional/mental health service with no follow-up	33.33%	13	23.08%	9	38.46%	15	5.13%	2	39
The service didn't meet my needs (wrong care)	44.74%	17	31.58%	12	21.05%	8	2.63%	1	38
The service didn't offer me the right type of support that I needed	42.11%	16	44.74%	17	10.53%	4	2.63%	1	38
Cost was prohibitive/ I couldn't afford to pay for it	37.50%	15	15.00%	6	40.00%	16	7.50%	3	40
Limited options/choice of service providers in my area	36.84%	14	26.32%	10	31.58%	12	5.26%	2	38
Worker changed frequently/ no consistent worker	43.24%	16	13.51%	5	40.54%	15	2.70%	1	37
Told that I didn't meet/no longer met criteria of the service	38.89%	14	11.11%	4	47.22%	17	2.78%	1	36
Lack of plan/goals/didn't seem to be progressing/going anywhere	44.44%	16	27.78%	10	22.22%	8	5.56%	2	36
Didn't need the full number of appointments as I felt better quickly	5.56%	2	8.33%	3	77.78%	28	8.33%	3	36
Other	33.33%	5	13.33%	2	40.00%	6	13.33%	2	15
Please comment:									14
								Answered	41

Thinking about the health professional or service that you decided not to engage with (continue with) in the past, what was the primary reason you decided to stop (disengage)?

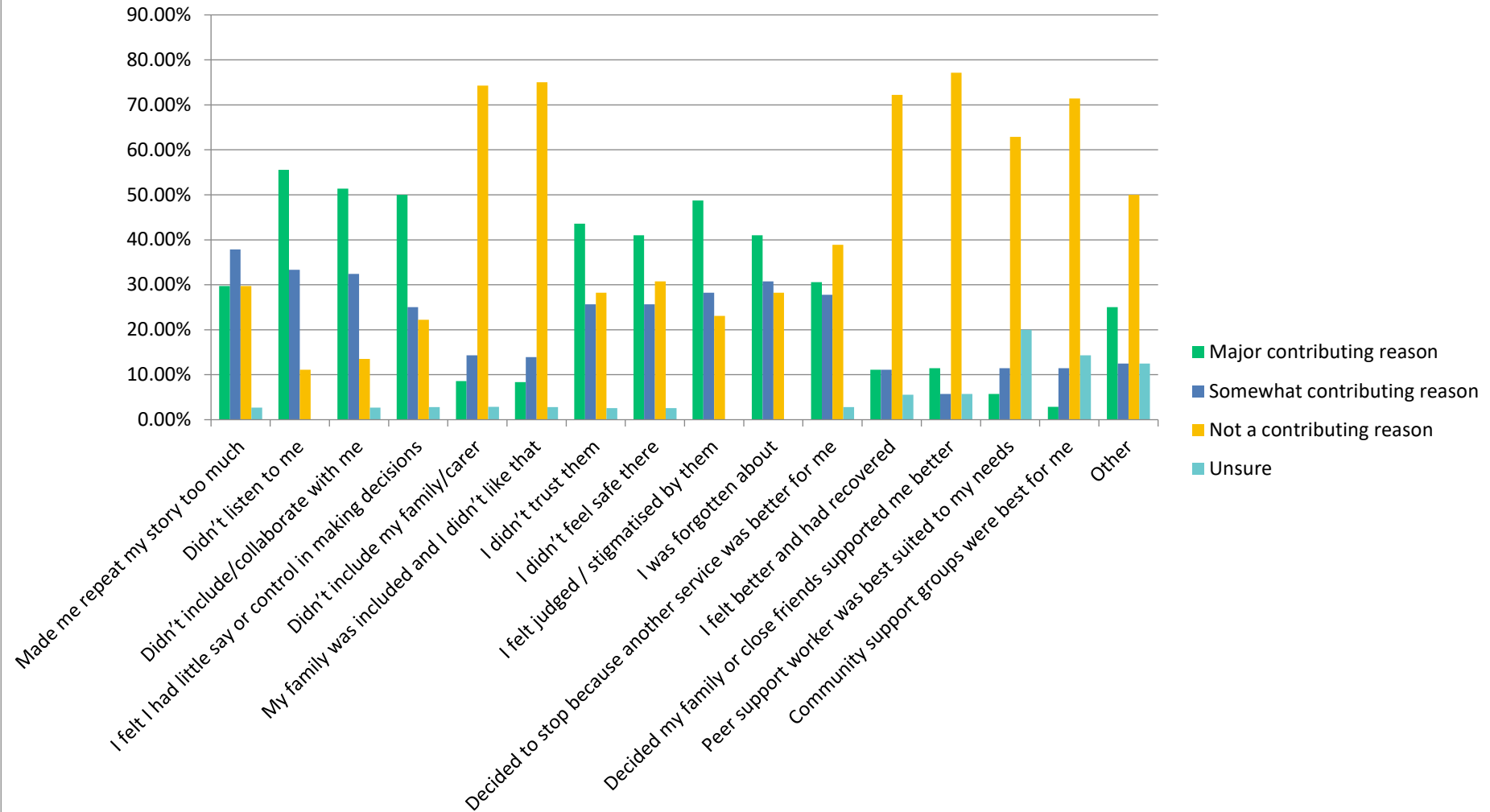


From a personal perspective, thinking about services that you decided not to engage with (continue with) in the past, what was the primary reason you decided to stop (disengage)?

	Major contributing reason		Somewhat contributing reason		Not a contributing reason		Unsure		Total
Made me repeat my story too much	29.73%	11	37.84%	14	29.73%	11	2.70%	1	37
Didn't listen to me	55.56%	20	33.33%	12	11.11%	4	0.00%	0	36
Didn't include/collaborate with me	51.35%	19	32.43%	12	13.51%	5	2.70%	1	37
I felt I had little say or control in making decisions	50.00%	18	25.00%	9	22.22%	8	2.78%	1	36
Didn't include my family/carer	8.57%	3	14.29%	5	74.29%	26	2.86%	1	35
My family was included and I didn't like that	8.33%	3	13.89%	5	75.00%	27	2.78%	1	36
I didn't trust them	43.59%	17	25.64%	10	28.21%	11	2.56%	1	39
I didn't feel safe there	41.03%	16	25.64%	10	30.77%	12	2.56%	1	39
I felt judged / stigmatised by them	48.72%	19	28.21%	11	23.08%	9	0.00%	0	39
I was forgotten about	41.03%	16	30.77%	12	28.21%	11	0.00%	0	39
Decided to stop because another service was better for me	30.56%	11	27.78%	10	38.89%	14	2.78%	1	36
I felt better and had recovered	11.11%	4	11.11%	4	72.22%	26	5.56%	2	36
Decided my family or close friends supported me better	11.43%	4	5.71%	2	77.14%	27	5.71%	2	35
Peer support worker was best suited to my needs	5.71%	2	11.43%	4	62.86%	22	20.00%	7	35
Community support groups were best for me	2.86%	1	11.43%	4	71.43%	25	14.29%	5	35
Other	25.00%	4	12.50%	2	50.00%	8	12.50%	2	16

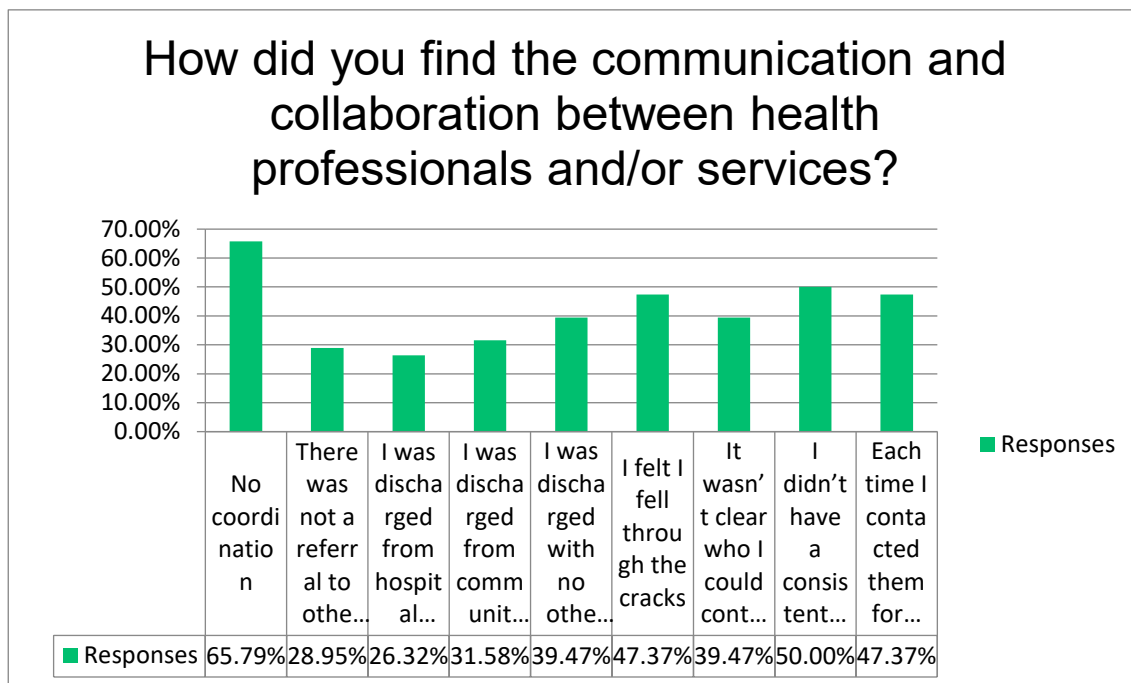
Answered 40
Skipped 46

From a personal perspective, thinking about services that you decided not to engage with (continue with) in the past, what was the primary reason you decided to stop (disengage)?



How did you find the communication and collaboration between health professionals and/or services?

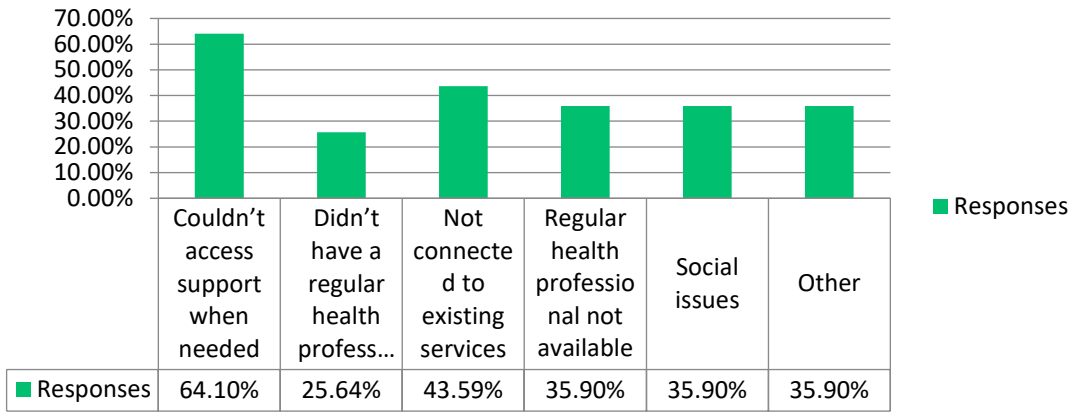
Answer Choices	Responses
No coordination	65.79% 25
There was not a referral to other services	28.95% 11
I was discharged from hospital with no referral or follow up	26.32% 10
I was discharged from community services before I was ready	31.58% 12
I was discharged with no other option	39.47% 15
I felt I fell through the cracks	47.37% 18
It wasn't clear who I could contact when I needed to	39.47% 15
I didn't have a consistent person who I could contact or speak to	50.00% 19
Each time I contacted them for help, I had to retell my story / they didn't seem to remember my situation, needs or preferences	47.37% 18
	Answered 38
	Skipped 48



If you have found yourself in a crisis, would you please indicate whether any of the following contributed to the deterioration in your condition:

Answer Choices	Responses	
Couldn't access support when needed	64.10%	25
Didn't have a regular health professional that I could get help from	25.64%	10
Not connected to existing services	43.59%	17
Regular health professional not available	35.90%	14
Social issues	35.90%	14
Other	35.90%	14
Please Comment		20
	Answered	38
	Skipped	48

If you have found yourself in a crisis, would you please indicate whether any of the following contributed to the deterioration in your condition:



Appendix B: NSW Data - Physical Health and Mental Health (LEA - Equally Well Report)

Which of these health professional(s) have you seen in the last 12 months, and did they ask about your general physical health, eg: blood pressure, cholesterol, diabetes, smoking, diet, exercise etc?

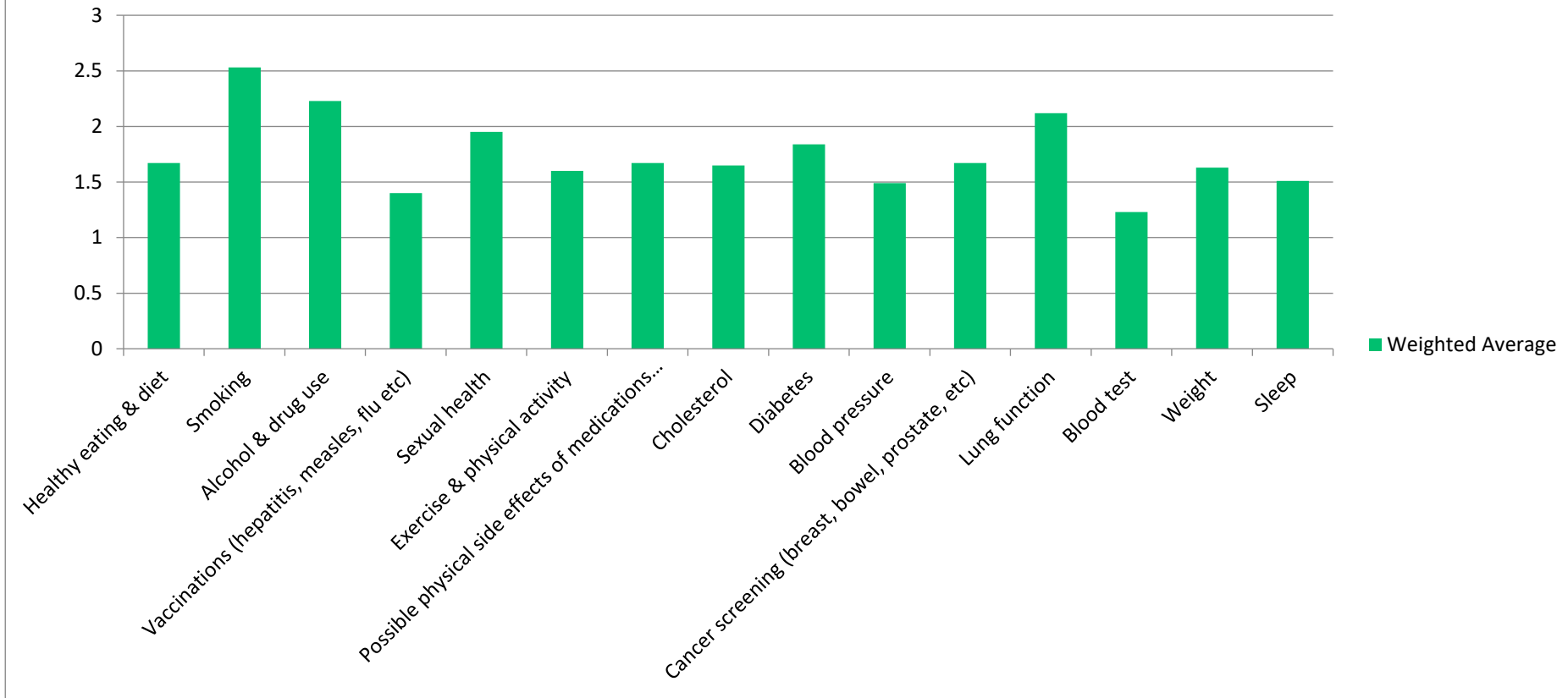
	I did not see this health professional in the past 12 months		I saw this health professional, but they did not ask about my physical health		I saw this health professional and they did ask about my physical health		Unsure or I can't remember		Total	Weighted Average
GP	4.65%	2	13.95%	6	81.40%	35	0.00%	0	43	2.77
Mental Health Nurse	62.16%	23	18.92%	7	10.81%	4	8.11%	3	37	1.65
Psychiatrist	52.63%	20	23.68%	9	18.42%	7	5.26%	2	38	1.76
Social Worker	75.68%	28	16.22%	6	5.41%	2	2.70%	1	37	1.35
Psychologist	25.64%	10	43.59%	17	28.21%	11	2.56%	1	39	2.08
NDIS Support Person	72.22%	26	11.11%	4	13.89%	5	2.78%	1	36	1.47
Pharmacist	21.05%	8	47.37%	18	28.95%	11	2.63%	1	38	2.13
Other allied health professionals e.g. physiotherapist, Occupational Therapist, dietitian, naturopath, etc.	46.15%	18	2.56%	1	43.59%	17	7.69%	3	39	2.13
									Answered	43
									Skipped	14

In the last 12 months has a GP talked to you about the following?

	Yes	No	Not applicable	Unsure or I can't remember	Total	Weighted Average
Healthy eating & diet	53.49% 23	34.88% 15	2.33% 1	9.30% 4	43	1.67
Smoking	13.95% 6	23.26% 10	58.14% 25	4.65% 2	43	2.53
Alcohol & drug use	25.58% 11	30.23% 13	39.53% 17	4.65% 2	43	2.23
Vaccinations (hepatitis, measles, flu etc)	65.12% 28	30.23% 13	4.65% 2	0.00% 0	43	1.4
Sexual health	20.93% 9	62.79% 27	16.28% 7	0.00% 0	43	1.95
Exercise & physical activity	51.16% 22	41.86% 18	2.33% 1	4.65% 2	43	1.6
Possible physical side effects of medications (e.g. weight gain, diabetes, heart disease)	48.84% 21	37.21% 16	11.63% 5	2.33% 1	43	1.67
Cholesterol	48.84% 21	41.86% 18	4.65% 2	4.65% 2	43	1.65
Diabetes	38.64% 17	40.91% 18	18.18% 8	2.27% 1	44	1.84
Blood pressure	65.12% 28	23.26% 10	9.30% 4	2.33% 1	43	1.49
Cancer screening (breast, bowel, prostate, etc)	44.19% 19	44.19% 19	11.63% 5	0.00% 0	43	1.67
Lung function	9.52% 4	73.81% 31	11.90% 5	4.76% 2	42	2.12
Blood test	79.55% 35	18.18% 8	2.27% 1	0.00% 0	44	1.23
Weight	44.19% 19	51.16% 22	2.33% 1	2.33% 1	43	1.63
Sleep	53.49% 23	44.19% 19	0.00% 0	2.33% 1	43	1.51

Answered 44
Skipped 13

In the last 12 months has a GP talked to you about the following?



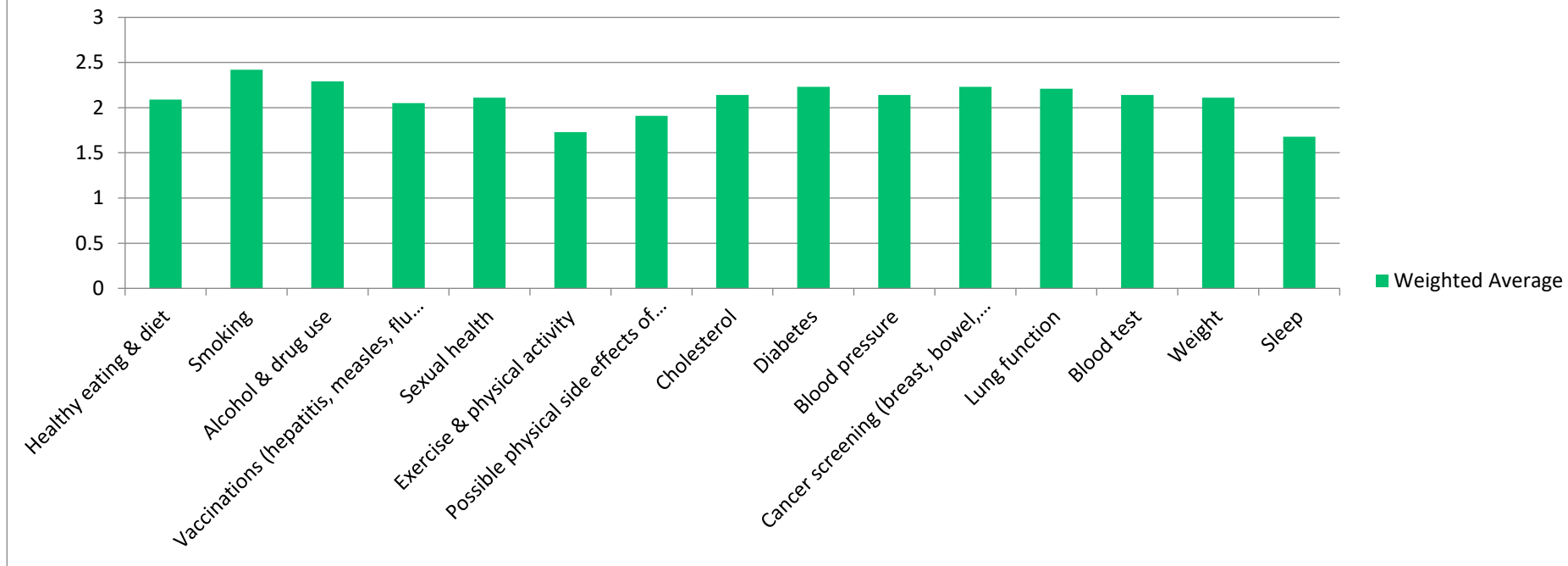
In the last 12 months has any Mental Health Professional other than your GP (e.g. psychologist, psychiatrist, mental health nurse, social worker, occupational therapist, etc) talked to you about the following?

	Yes	No	Not applicable	Unsure or I can't remember	Total	Weighted Average
Healthy eating & diet	23.26% 10	53.49% 23	13.95% 6	9.30% 4	43	2.09
Smoking	6.98% 3	44.19% 19	48.84% 21	0.00% 0	43	2.42
Alcohol & drug use	19.05% 8	38.10% 16	38.10% 16	4.76% 2	42	2.29
Vaccinations (hepatitis, measles, flu etc)	16.67% 7	64.29% 27	16.67% 7	2.38% 1	42	2.05
Sexual health	15.91% 7	59.09% 26	22.73% 10	2.27% 1	44	2.11
Exercise & physical activity	43.18% 19	40.91% 18	15.91% 7	0.00% 0	44	1.73
Possible physical side effects of medications (e.g. weight gain, diabetes, heart disease)	27.27% 12	54.55% 24	18.18% 8	0.00% 0	44	1.91
Cholesterol	4.65% 2	76.74% 33	18.60% 8	0.00% 0	43	2.14
Diabetes	6.82% 3	63.64% 28	29.55% 13	0.00% 0	44	2.23
Blood pressure	6.98% 3	72.09% 31	20.93% 9	0.00% 0	43	2.14
Cancer screening (breast, bowel, prostate, etc)	4.65% 2	67.44% 29	27.91% 12	0.00% 0	43	2.23
Lung function	4.65% 2	69.77% 30	25.58% 11	0.00% 0	43	2.21
Blood test	11.63% 5	65.12% 28	20.93% 9	2.33% 1	43	2.14
Weight	15.91% 7	59.09% 26	22.73% 10	2.27% 1	44	2.11
Sleep	47.73% 21	36.36% 16	15.91% 7	0.00% 0	44	1.68

Answered 44

Skipped 13

In the last 12 months has any Mental Health Professional other than your GP (e.g. psychologist, psychiatrist, mental health nurse, social worker, occupational therapist, etc) talked to you about the following?



Other than a GP, which of the following reflects your overall or general experiences when seeking support from a mental health professional (e.g. mental health nurse, psychologist, psychiatrist, social worker, occupational therapist, etc)?

	Never		Rarely		Sometimes		Often		Always		Unsure		Total	Weighted Average
They routinely ask about my physical health.	23.26%	10	27.91%	12	39.53%	17	4.65%	2	4.65%	2	0.00%	0	43	2.4
They take seriously any concerns I raise about my physical health.	9.30%	4	18.60%	8	23.26%	10	13.95%	6	30.23%	13	4.65%	2	43	3.51
They are interested in my whole health (e.g. social connection/engagement, lifegoals), not just my mental health diagnosis.	16.28%	7	11.63%	5	27.91%	12	20.93%	9	23.26%	10	0.00%	0	43	3.23
They respect and listen to my concerns about medications.	13.95%	6	18.60%	8	20.93%	9	16.28%	7	25.58%	11	4.65%	2	43	3.35
They provide me with clear information about any tests, medication or concerns in a way that I can understand.	19.05%	8	19.05%	8	28.57%	12	14.29%	6	16.67%	7	2.38%	1	42	2.98
They keep me informed and include me in each step and decision about my physical health care.	23.26%	10	18.60%	8	18.60%	8	13.95%	6	18.60%	8	6.98%	3	43	3.07
They encourage me to be an active participant in my own physical self-care.	9.30%	4	16.28%	7	30.23%	13	18.60%	8	23.26%	10	2.33%	1	43	3.37
I can afford to see them when and as often as I need to.	9.30%	4	16.28%	7	32.56%	14	18.60%	8	18.60%	8	4.65%	2	43	3.35
I have enough access to allied health professionals to support my physical health (e.g. physiotherapists, dietitians).	11.63%	5	23.26%	10	25.58%	11	16.28%	7	16.28%	7	6.98%	3	43	3.23
When I have needed to go to hospital or to an emergency department for my mental health, the health professionals have asked about my physical health.	34.88%	15	11.63%	5	16.28%	7	13.95%	6	4.65%	2	18.60%	8	43	2.98

Answered 43 / Skipped 14