

**AIDS ACTION COUNCIL
OF THE ACT**

**DIETITIAN CLINIC
EVALUATION
REPORT**



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1 BACKGROUND

Nutrition can have a big impact on a person's health and wellbeing. This is especially so for people living with HIV, who have the additional challenge of managing the interaction between their medications and their diet, where their diet can impact the effectiveness of HIV medications.

The AIDS Action Council (the Council) has been independently funding a dietician clinic for people living with HIV in the ACT and regional communities surrounding the ACT for over ten years. The Dietitian Clinic aims to increase the health-related quality of life for people living with HIV, by providing tailored information and support for improving their health and wellbeing.

In 2016, the Council received funding from the AIDS Trust of Australia to evaluate the Clinics. The goal of the evaluation was to measure the effectiveness of the Clinic at supporting people living with HIV to improve their health and wellbeing.

2 METHODOLOGY

The evaluation was designed to measure changes to the health-related quality of life (HRQoL) of people living with HIV as a result of attending the Dietitian Clinic. Health-related quality of life is a widely used measure of health and wellbeing for people with chronic illness. HRQoL measure the extent to which a person's health impacts their overall sense of wellbeing, including their physical, mental, emotional and social functioning.

Health-related quality of life (HRQoL) is an important measure of HIV care. There are a number of well-established instruments for measuring the HRQoL of PLHIV, however, because the nature of the illness has evolved so quickly, the instruments must be updated regularly to stay relevant. Because this evaluation does not need to be replicated or extrapolated to the population, this evaluation uses an independent methodology created specifically for this purpose. The questions, however, are informed by several HIV-specific Health Related Quality of Life Assessments.

THE EVALUATION MEASURED CHANGE ACROSS FOUR KEY AREAS:

- 1 Access to information and services;
- 2 Attitude towards medication and treatment;
- 3 Health and wellbeing; and
- 4 Social connectedness, support and resilience.

THE FOLLOWING METHODS WERE USED:

- 1 Review of bloodwork;
- 2 Pre and post treatment surveys; and
- 3 Case studies – based on case notes, observation by the Dietician and Treatments Officer and/or interviews with clients.

The results of these methods, particularly self-reported changes in wellbeing by service users, will be triangulated with an assessment and verification process between the evaluation consultant and the Dietician and Treatments Officer.

LIMITATIONS

Pre and post treatment surveys

The methodology was designed on the basis that the same people would attend multiple clinics so we could track their progress over the course of the year. Unfortunately, of the twelve clients that consented to participate in the study, the majority (eight) attended two or less appointments during the evaluation period. This makes it difficult to measure changes in the pre and post treatment surveys and to attribute these to the Clinic. Therefore, the decision was made not to compare data from the pre and post treatment surveys but instead to focus on the client's evaluation of the Clinic.

Review of bloodwork

It was anticipated that clients would attend multiple Clinics over the year and bring their bloodwork for review to each clinic. However, as discussed above, only four of the twelve people that consented to participating in the research attended more than two clinics. Further, few people consistently brought blood work in for review. As a result, it was decided not to include bloodwork in this evaluation.





ETHICS

This evaluation is designed and will be conducted in accordance with the National Statement on Ethical Conduct in Human Research¹, which seeks to promote ethically good human research by fostering research that is of benefit to the community and ensuring that participants are accorded the respect and protection that is due to them.

The design, review and conduct of the evaluation of the Dietitian and Treatments Clinic will reflect the values and principles of ethical conduct as outlined in the Statement, including:

- Research merit and integrity – the research is methodologically sound, contributes to knowledge and understanding in the area of enquiry and is conducted by experienced researchers that demonstrate integrity and honesty;
- Justice – the research is based on principles of equality and fairness;
- Beneficence - the likely benefit of the research justifies any risks of harm or discomfort to participants; and
- Respect – the research prioritises the welfare of participants and respects their privacy, confidentiality and cultural sensitivities.

As per the National Statement, participation in the evaluation will be founded on the requirement of consent that is voluntary choice, and is based on sufficient information and adequate understanding of both the proposed research and the implications of participation in it.

To participate in the evaluation, participants were required to complete an informed consent form, which provided information about the purpose of the evaluation; the evaluation process; confidentiality; how their data will be used; and their rights and responsibilities (see Appendix A).

1 The National Statement on Ethical Conduct in Human Research (2007) Available from <https://www.nhmrc.gov.au/guidelines-publications/e72>

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SURVEY RESULTS

ABOUT THE PARTICIPANTS

- Eight men completed pre and post surveys.
- Participant ages ranged across the spectrum from 18- 25 to 65+.
- Seven were from the ACT and one from NSW.
- One person identified as culturally and linguistically diverse and no people identified as Aboriginal or Torres Strait Islander.
- The length of time participants have been living with HIV ranges from six weeks to over 25 years.
- Five of the eight participants reported undetectable viral loads on their most recent test and three reported a detectable viral load. Participants reported that their results have been consistent, with the exception of the person who was diagnosed in the last six weeks.

REASONS PARTICIPANTS ATTENDED THE CLINIC:

Managing weight gain

... I wish to see what help is on offer and the clinic is an easily accessible source of reliable information.

The advice is helpful

Chronic IBS and Gastroparesis and other Gastro Intestinal issues over the last six year have had periodic hospital admissions

General health and dietary check

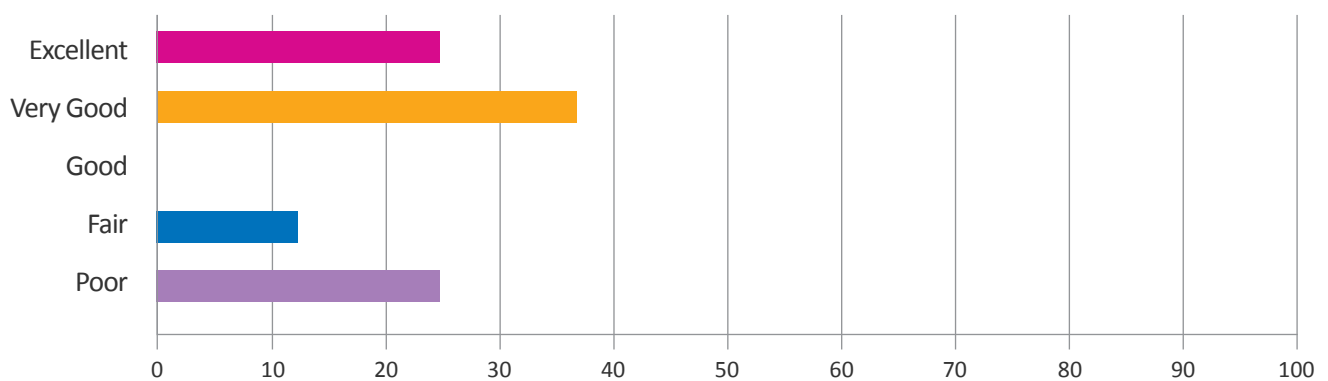
The fact that antiretroviral therapy continues to raise lipid levels significantly for me is a constant issue, and this needs close monitoring by experienced HIV knowledgeable health professionals to reduce these dangerous lipid levels by healthy lifestyle and dietary management, which is on-going

Managing my weight and understanding what I should be eating and doing to give myself the best chance of survival and to enhance the treatment of mends

GI upsets

HEALTH AND WELLBEING OF PARTICIPANTS BEFORE ATTENDING THE CLINIC

Participant ratings of their health during the four weeks prior to attending the Clinic

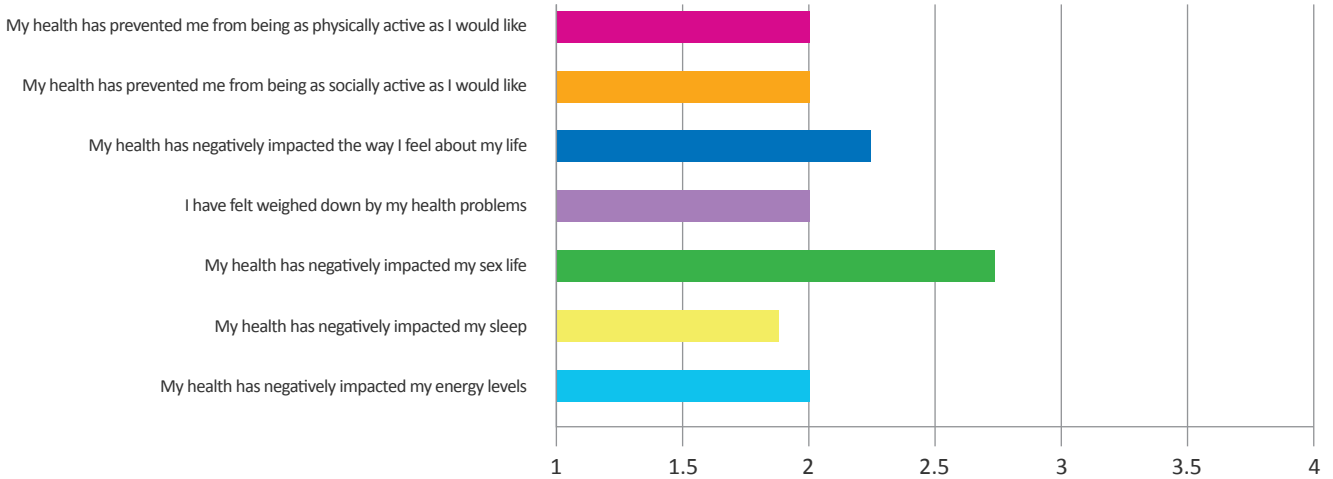


Impact of participants' health on their quality of life in the four weeks prior to the Clinic

DURING THE PAST FOUR WEEKS, HOW OFTEN HAS THE FOLLOWING OCCURRED?	None of the time	A little of the time	A lot of the time	All of the time
My health has negatively impacted my energy levels	3	2	3	0
My health has negatively impacted my sleep	4	2	1	1
My health has negatively impacted my sex life	2	2	0	4
I have felt weighed down by my health problems	3	2	3	0
My health has negatively impacted the way I feel about my life	2	3	2	1
My health has prevented me from being as socially active as I would like	4	0	4	0
My health has prevented me from being as physically active as I would like	3	3	1	1

AVERAGE OCCURANCE

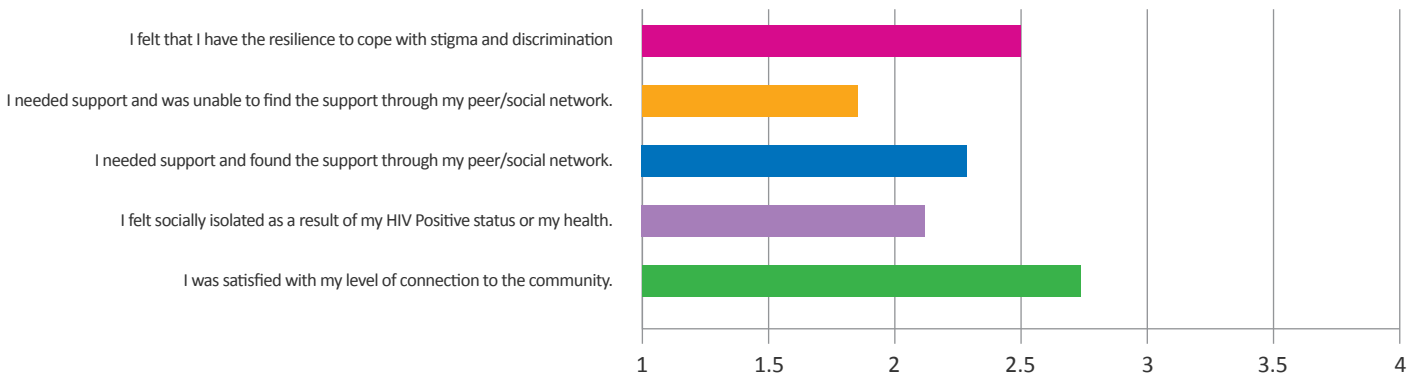
1 = NONE OF THE TIME 4 = ALL OF THE TIME



DURING THE LAST FOUR WEEKS, HOW OFTEN HAS THE FOLLOWING OCCURRED?	None of the time	A little of the time	A lot of the time	All of the time
I was satisfied with my level of connection to the community.	0	4	2	2
I felt socially isolated as a result of my HIV Positive status or my health.	3	2	2	1
I needed support and found the support through my peer/social network.	2	3	0	2
I needed support and was unable to find the support through my peer/social network.	3	2	2	0
I felt that I have the resilience to cope with stigma and discrimination	1	3	3	1

AVERAGE OCCURANCE

1 = NONE OF THE TIME 4 = ALL OF THE TIME



FINDINGS ABOUT THE RELEVANCE AND QUALITY OF THE CLINIC

THE CLINIC IS HIGHLY RELEVANT TO PEOPLE LIVING WITH HIV. THE AVERAGE RATING FOR RELEVANCE WAS 4.5/5.

AVERAGE RELEVANCE RATING 

“Jenny [the dietitian] would tailor her advice and suggestions based on the individual which was fantastic. She also gives me the confidence to take charge.”

“This clinic is so essential to the HIV positive community. It has provided someone who is focused on the individual and their needs. I have come a long way in my health with the guidance of Jenny [the Dietitian].”

THE CLINIC IS VIEWED AS A VERY HIGH-QUALITY SERVICE. THE AVERAGE QUALITY RATING WAS 4.6/5.

AVERAGE RELEVANCE RATING 

FINDINGS ABOUT THE EFFECTIVENESS OF THE CLINIC AT IMPROVING THE HEALTH AND WELLBEING OF PEOPLE LIVING WITH HIV

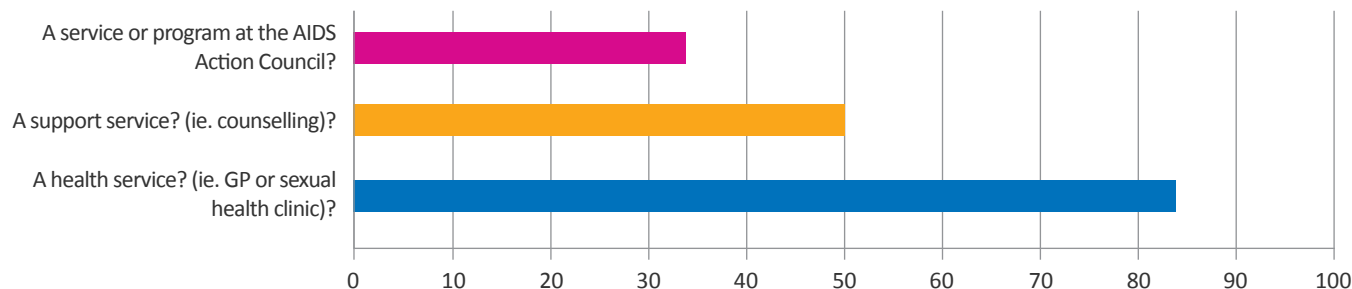
88% OF CLIENTS SURVEYED EXPERIENCED IMPROVED HEALTH OR WELLBEING AS A RESULT OF ATTENDING THE CLINIC.

“Working with Jenny [the Dietitian] to identify food groups or adding other solutions have been amazing. Specially working on coping mechanisms to minimising the episodes.”

“Allowed me to keep up to date with good clear advice, especially regarding dietary supplements, exercise regimes and so on, to sort out what is really beneficial to my health, to that of just marketing hype of various advertised products. The advice has helped me make good decisions, in order to cut through the haze, of what is good, and what is not so good.”

75% of clients surveyed reported that the Clinic increased their access to the information, social networks, resources and/or services they need to improve their health and wellbeing in the future. Further, as a result of attending the Clinic, 83% of clients surveyed had accessed a health service, 50% had accessed a support service (i.e. counselling) and 33% had accessed a service or program at the AIDS Action Council.

% OF PARTICIPANTS THAT ACCESSED THE FOLLOWING SERVICES AS A RESULT OF ATTENDING THE CLINIC



CASE STUDY

Jason (not their real name), attended the Clinic in February 2016. He had previously attended the Clinic in 2015 and his health had deteriorated since then. Jason had gained up to three kilos since attending the Clinic in 2015 and his lipids and blood glucose levels had increased. Jason explained that he has recently begun living with someone and they more regularly eat takeaway and drink alcohol.

Jason attended the Clinic again in March, reporting that he was admitted into hospital with abdominal pain, diarrhea, bloating and dehydration. The Dietitian discussed his food choices and how he can reduce his gastrointestinal stress while also managing his diabetes, such as by omitting some foods and increasing fiber. The Dietitian also stressed the importance of having regular colonoscopies, after discovering Jason had not had one since 2011.

Jason returned in June. He reported that he had had a colonoscopy which showed he had a polyp which was removed. His bowels were still a problem but he had noticed some improvement since implementing the diet changes recommended by the Dietitian. The Dietitian worked with Jason to tweak his diet further.

Jason returned again at the end of the year. He had not had any further hospital admissions and his gastrointestinal issues were easing. He reported that he is eating better and has a more positive approach to his diet and his diabetes. He is slowly reintroducing exercise back into his lifestyle and his weight is starting to slowly decrease.

CONCLUSION

While the methodology did not work as expected, the survey results are clear that the clients surveyed highly value the Dietitian Clinic. It is a quality service, relevant to their needs and has resulted in health and wellbeing outcomes for the vast majority of respondents.

Because clients attend the Dietitian Clinic on an at-needs basis, rather than for regular appointments, the AIDS Action Council have developed a new approach to evaluating this program. Clients will be able to complete an evaluation after attending every Clinic through a tablet device available at the Clinic or on their own mobile devices. The process is quick and simple and will enable the Council to collect data regularly, rather than through a one-off evaluation.

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APPENDIX A INFORMED CONSENT FORM

CONSENT FORM TO PARTICIPATE IN THE EVALUATION OF THE DIETITIAN AND TREATMENTS CLINIC

PART 1: INFORMATION SHEET

Before consenting to participate in this evaluation, it is important that you understand why we are doing the evaluation, what we will be asking of you and how your information will be used.

Background

The AIDS Action Council (the Council) has been delivering a Dietitian and Treatments Clinic for people living with HIV (PLHIV) in the ACT and regional communities surrounding the ACT for five years. The goal of the Clinic is to improve the health of people living with HIV, increase their quality of life and help to reduce the level of HIV transmissions to zero by 2020.

In 2016, the Council received funding from the AIDS Trust of Australia so the Council could increase the number of clinics from four to eight clinics per year. As part of this, the Council also received funding to undertake an evaluation of the effectiveness of the Clinic.

What is the purpose of the evaluation?

The purpose of the evaluation is to measure if the Clinic is making a difference to the health and wellbeing of people attending. This will help the Council to demonstrate the value of the Clinic and assist in attracting funds to expand the service in the future.

The Council has contracted an independent consultant with specialist expertise in evaluations to undertake the evaluation. The consultant will work closely with Council staff and the Dietitian and Treatments Officer to conduct the evaluation.

THIS EVALUATION IS DESIGNED TO MEASURE THE CONTRIBUTION OF THE CLINIC TO CLIENTS' HEALTH-RELATED QUALITY OF LIFE. THE EVALUATION WILL MEASURE CHANGE ACROSS FOUR KEY AREAS:

1. Health and wellbeing;
2. Adherence to and attitude towards medication and treatment regimens;
3. Social connectedness, support and resilience; and
4. Access to information and services;

THE EVALUATION WILL USE:

1. Pre and post treatment surveys;
2. Review of bloodwork;
3. Review of case files; and
4. Case studies – based on case notes, observation by the Dietitian and Treatments Officer and/or interviews with clients.

What does participation involve?

All clients of the Dietitian and Treatments Clinic are invited to participate in the evaluation. The evaluation will take place from February 23rd to December 16th 2016. As discussed above, the evaluation will involve:

1. A short questionnaire prior to a client's first session at the Clinic and again at the completion of the Clinic in December 2016. This questionnaire can be completed in hardcopy or electronically.
2. The review of participants' blood tests to measure changes in key health indicators – primarily, Lipid profile and viral loads, however, other indicators may be used where relevant.
3. The review of case files to identify change in key health-related quality of life indicators (such as change in diet and lifestyle, reduction of side effects, increased feelings of wellbeing etc.).
4. Case studies – based on case notes, observation by the Dietitian and Treatments Officer and/or interviews with clients.

In order to participate in the evaluation, clients will be asked to consent to participating in the questionnaire and to have their tests and case files reviewed. Clients may or may not be asked to participate in a case study and they may choose whether or not they would like to do this.

We will also be collecting data about the type of information and support offered through the clinic, including:

- Number of referrals or recommendations to services provided; and
- Number of occasions information and support about treatment options, managing health and wellbeing, and sexual health was provided.

How will my confidentiality be protected?

Any information collected about you in connection with this evaluation will remain confidential and will only be disclosed for reasons other than those stated in the consent form with your permission or as required by law.

All data will be de-identified before it is shared beyond the immediate research team. This means that your information cannot be connected back to you as an individual.

During the evaluation process, you will be given a Participation Code (comprising three digits and the first three letters of your surname) to minimise the number of people that have access to your individually identifiable data before it is de-identified. The Dietitian and Treatments Officer will have complete access to your data and it may be necessary for the Evaluation Consultant and key staff at the Council to have access in some instances, however, this will be minimised through the use of the Participation Code.

Please see the Council's [Clients' Rights and Responsibilities](#) information sheet for more information on the Council's privacy policy.

How will the data be used?

Once the data has been de-identified so that no participants can be identified, the results will be compiled into a report. This report may be shared with a number of audiences, including potential government and non-government funders and other stakeholders, in accordance with the purpose of this evaluation: *...to measure the effectiveness of the Clinic to support the development of an evidence base for attracting funding and increasing availability of the service in the future.*

All data, including individually identifiable data will be kept for 12 months after completion of the evaluation as per the Australian Code for the Responsible Conduct of Research.²

Are there any risks I should be aware of?

There are no foreseeable risks of participating in this evaluation.

What if I am not happy with how I am treated?

All service users have rights and responsibilities. These are outlined in detail in the Clients' Rights and Responsibilities information sheet that is available to all clients on request. In the event that you are not satisfied with the way that you have been treated, please refer to the information sheet for more details about your rights and the process for making complaints.

If you have any concerns about this evaluation you are also welcome to contact the Executive Director of the AIDS Action Council, Philippa Moss on Philippa.Moss@aidsaction.org.au or 6257 2855.

What if I change my mind?

You can withdraw from the evaluation at any time simply by informing the Dietitian and Treatments Officer or a Council staff member. Your withdrawal will not affect your treatment at the Clinic or your relationship with staff.

Thank you for reading the above information. If you would like to participate in the evaluation of the Dietitian and Treatment Clinic please complete the consent form on the following page.

² National Health and Medical Research Council, Australian Research Council, 2007, Australian Code for the Responsible Conduct of Research. Available from https://www.nhmrc.gov.au/_files_nhmrc/publications/attachments/r39.pdf

PART 2: CONSENT FORM

PARTICIPANT CODE:

To be completed by office administration

I, (full name) _____

of (address) _____

have read and understand the information provided in the attached information sheet. I understand the purpose of the evaluation, what will be involved in the study and how my information will be used.

I understand that my participation in this evaluation will not affect my treatment in the Clinic or my relationship with staff. I understand that I can withdraw my consent at any time.

In giving my consent, I give the evaluation team, including the Evaluation Consultant and key Council staff, access to my medical records and case files. I understand the evaluation team will ensure that this information is kept confidential.

After considering this information, I give my free and willing consent to participate in the evaluation of the Dietitian and Treatment Clinic at the AIDS Action Council of the ACT.

Name: (please print) _____

Date _____

Signature: _____

Please select the relevant boxes below to indicate how you would like to participate:

Please email me the questionnaire so I can complete it online. My email address is:

Please provide me with a hardcopy questionnaire.

I am happy to be contacted about using my experience at the Clinic a case study.

Please provide your contact details so we can send you the final questionnaire at the end of the Clinic.

Phone: _____

Email: _____



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