

Case Study: Primary aldosteronism plain language brochures

Purchasing and applying the standard

Enliven Victoria purchased the ISO Standard in October 2023. The brochures were completed in January 2024 using the standard.

What was the problem or issue we were trying to tackle?

We were approached by Monash University and the Hudson Institute of Medical Research in Australia to create some plain language resources about primary aldosteronism. This is a condition where the adrenal glands produce too much of a hormone called aldosterone. This can lead to sustained high blood pressure, cardiovascular damage and other illnesses. The condition can be very serious and in some cases treatment involves surgery.

The university wanted to raise awareness of the condition and encourage people with high blood pressure to get tested. This project was to form part of a research study to increase testing, diagnosis and treatment of this illness. The condition is not well understood, and testing rates are low.

How did we gather information about the problem?

We reviewed current information about the condition and we liaised closely with the research team, which included clinicians. While information was available on the internet, it was complex and not easy to find or understand.

The research team identified the need for plain language resources to improve understanding and increase testing rates and they had data to support this need. Doctors also needed plain language resources to help them explain the condition, the risks associated with this condition, the multiple tests that can lead to a confirmed diagnosis and the treatment options. The research study needed to give people with high blood pressure information they could use to make informed decisions about their health.

What was the scope of our project?

The scope was to produce 3 plain language resources for printing:

- Understanding primary aldosteronism
- Testing for primary aldosteronism
- Treating primary aldosteronism

Doctors were going to give the brochures to their patients with high blood pressure in their medical clinics. We were asked to include community testing of the resources while they were being developed and for the final product. It is important to note that we always community test with multicultural communities because Australia is one of the most culturally diverse countries in the world.

Readers needed to be able to find the information, understand the information and use it to decide whether to get tested or treated if a positive diagnosis was made.

How did we apply the plain language principles?

Principle 1: Relevant

Each brochure was designed to be relevant to the reader, at each stage of their journey.

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- People with high blood pressure are at risk of primary aldosteronism. Our first brochure was aimed at these patients, to increase their understanding of the condition and of the need to get tested.
- If a patient was at risk of having this condition, the second brochure provided these patients with the details of what tests are needed, what the tests tell the doctor and what they involve.
- If testing confirmed that the patient has primary aldosteronism, the third brochure explained the treatment options so that these patients could make an informed decision.

Principle 2: Findable

We used clear and meaningful headings and sub-headings. We used images to help with understanding.

Because there were multiple tests for patients to go through to get to a final diagnosis, we used a table format to display this information. The table included the name of each test, details about the test, how long it takes, what happens if the test is positive and what happens next. This was designed to allow the patient to know exactly where to find particular information about each test as they progressed through them.

Information in all brochures was presented in chronological order and we ensured the document met accessibility standards.

Principle 3: Understandable

We removed words that were unnecessary technical, medical or unfamiliar, and we explained those terms that the patient needed to know. We used familiar language as well as lists (dot points) and numbered steps.

The brochures were sometimes lengthier than the information that was available on the internet but it is important to explain concepts that the reader needs to know about. When focusing on informed consent for medical interventions, the information needs to be complete and understandable for a person to use it to make an informed decision.

Principle 4: Usable

The brochures were to be given to people with high blood pressure so that they could use the information to decide whether to be tested or treated. The information was to be presented to patients in chronological order and as needed. For example, the brochure about treatment was only to be given to those who had a positive diagnosis. Following the first 3 principles helped us to make the documents usable.

How did we plan this project?

We met with the research team coordinator who provided us with details about the study and about the scope of the project. We assigned a plain language officer to apply the ISO Plain Language Standard to the brochures.

We assigned time to scope the information available on this condition and to verify the information with the clinical team. We recruited 2 community testers early in the process. One had recently migrated to Australia with some limited English proficiency and knowledge of the Australian healthcare system and the other had been in Australia for a few years and

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could speak and read English well. We prefer to use 4 community testers, but the budget only allowed for 2.

We set up milestones for the plain language officer and research team coordinator and decided how many reviews the clinical team would need to verify accuracy of our content. We set out a timeframe for the project and assigned additional resources such as brochure design. The evaluation of the brochures forms part of the research study and was not in scope for our contract.

So how did the project go?

The project went well but we did have some timeframe challenges. The clinical team needed more clinical expert reviews than originally considered, which delayed the project by a month.

It was vital that the clinical team felt comfortable with the content and with our rationale for changing terminology. Using the standard was particularly useful here and gave us a sound basis for our choices. One example was using a table in the Testing for Primary Aldosteronism brochure. At first the clinical team was not convinced that this approach was best. Applying the standard and using community testing showed the team that the table helps readers to find the information they need. The additional reviews by the clinical team were vital in verifying the accuracy of the information.

What did we learn? It's important to understand how much your customer or client wants to be involved in the plain language conversion process. **A co-design process with clinicians and community testers may have been more resource intensive but would have helped in raising their understanding of the 4 principles and reaching consensus quicker.**

What outcomes did we achieve?

It's too early to say whether the brochures led to increased understanding, uptake of testing or earlier diagnosis and treatment. This will form part of the broader research study.

Our community testers did help us to improve the brochures by highlighting where they would need more explanation or information and if there were terms or concepts they did not understand.

- They understood the condition and the different types of primary aldosteronism.
- They knew what tests would need to be performed, why and how the tests were conducted, and what the tests told their doctor.
- They understood what treatment options were available for the different types of the condition.

Here is some final feedback from our community testers, in their words.

- **Tester 1:** "I loved these. I can see the previous feedback was taken into account (that makes me happy). Simple explanations and so easy to understand. I didn't need to read it again to understand it. Layout is lovely and colours are just enough to not distract from the info. My son understood this all at first read, he is 13!"
"Brochure 2 as a table looks great and straight to the point. People can skim through it and choose what they want to read when they need it... to give info to someone that only wants to know about one test at a time the table is better. They look amazing and are easy to understand, and will be easy to interpret when need be."

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- **Tester 2:** “design is really awesome and no changes needed to the text. You did very good work.”
“There were 2 versions of brochure 2. One of them is a TABLE and the other is just TEXT. Both are good. Brochure easy to understand and you mentioned details as well. But I like more Brochure 2 TABLE. It’s more look good and easier to understand as well. I can explain also my friend and family and community also. It’s more helpful for us. Thanks 🙏 a lot. I am hoping in future we will get more useful information about things related to our body and issues like this. Thanks again.”