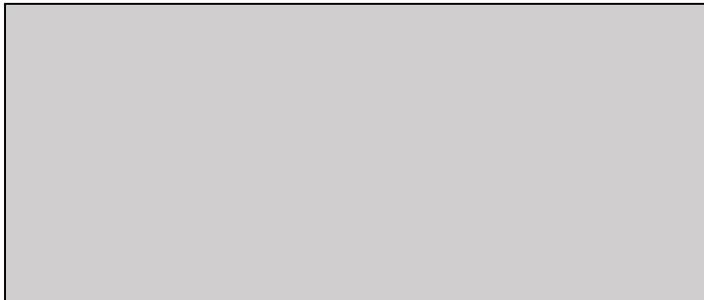




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RE: HCCA Feedback on the Canberra Sexual Health Fact Sheets (Batch 2)

The Health Care Consumers' Association (HCCA) of the ACT was formed over 30 years ago to provide a voice for consumers on local health issues and now provides opportunities for health care consumers in the ACT to participate in all levels of health service planning, policy development and decision making.

HCCA welcomes the opportunity to provide feedback on the Canberra Sexual Health Fact Sheets (Batch 2). HCCA recognises the importance of documents like these in developing the expertise of health consumers to actively engage with our own health care, understand the health care system and to be able to participate as equal partners with health professionals to make informed decisions about our own and our family's health. Health literacy is an essential right of a health care consumer as addressed in the Australian Charter of Health care Rights, particularly the charter rights of access, communication and participation.

General Comments

The five brochures being reviewed are **Gonorrhoea, Cryotherapy After Care, Genital Herpes, HIV Testing and Genital Skin Care**. Overall the fact sheets are clear and easy to follow with a logical flow. HCCA appreciated the incorporation of previous suggestions made with batch 1 of the fact sheets, particularly the addition of the *Useful Websites* section and information on where you can be tested or receive treatment in the ACT. HCCA also appreciates the link to information in other languages. After consultation with our members the overall feedback was positive. Those consulted felt the information is clearly written, and that the provision of further information was useful.

There are still some areas of the brochures that do not read as clearly due to wording and sentence structure. Whilst some of this is addressed in this document we presume there is an internal ACT Health editing/ proof reading process to aid with this. Some of the brochures still feel slightly confusing to read through a

suggestion may be to read current sheets of information provided (i.e. the HIV fact sheet from the AIDS Action Council) for possible layout, flow and information included.

You informed us that these brochures are the main source of written information provided to patients attending the Canberra Sexual Health Clinic (CSHC), and also made available on the CSHC website. Provision of this information on the website and in the clinic is excellent but many of those we consulted stated that the information in some cases seemed quite clinical and harsh and wanted to know the context in which this information is given, During a consultation? In the waiting room? After a consultation? Considering at what point a consumer takes in this valuable but at times quite detailed and complex information is essential ensuring good uptake of this patient information. Many Consumers we consulted also suggested these documents could also be used as part of wider information strategy using other platforms depending on who your target audiences are within the ACT community to increase health literacy in the community about sexual health.

'I thought the genital skin care handout was a great idea given that our society is so flooded with highly perfumed (and possibly irritant), products, They should get this information out into our communities!' –Consumer Feedback on Batch two of CSHC Brochures.

Specific Comments

Specific comments will be given for each fact sheet under the headings within each document.

Gonorrhoea

Overall this brochure is clearly laid out with appropriate information. In the second sentence it may clearer to specify that the cervix is a passage found at the top of the vagina. In the third sentence we suggest including *in men the infection usually occurs in the urethra, where you pass urine*. Sentences like these, use of clarifying statements may be useful to explain words may be unfamiliar to some consumers.

How can I get infected with gonorrhoea?

We suggest moving the above heading to top of the fact sheet under the introductory paragraph and amending the information for clarity as below;

Gonorrhoea is transmitted by having vaginal, anal or oral sex without using a condom with someone who is currently infected with gonorrhoea.

What are the symptoms of gonorrhoea?

For this section all symptoms for areas that could be infected are discussed except the symptoms of infections in the eyes. Under the sub-heading *Woman* the first two sentences are unclear. We suggest changing it to; *Most woman with a gonorrhoea*

infection do not show any signs or symptoms, if symptoms do occur they may include:

The first dot point under this is *a change in vaginal discharge* this could be made clearer by including a sentence describing what that change would be. This comment is also relevant for dot point 5 which states a possible symptom could be *anal discharge and discomfort* it should be made clear what discomfort means in this context – is this referring to pain?

How does someone get infected with gonorrhoea?

We suggest amending the sentence below this heading to read *.../...with someone who is currently infected with gonorrhoea.*

How is gonorrhoea diagnosed?

The second sentence could to be reworded as it sounds as though the swab is being removed from the patient. The section also includes a level of detail that may not be needed for consumers who need immediate information about their current symptoms and infection. We suggest the rewording below:

Diagnosis is based on the above symptoms and clinical signs, and laboratory testing. Laboratory testing includes the examination of a urine sample and/or a sample collected with a swab (a long cotton bud) from the infected body site eg the cervix, vagina, urethra, anus, eye or throat.

Practitioners who have access to a microscope may be able to diagnose gonorrhoea in their clinic or office and can give you quick advice. However the sample will also be sent to a laboratory for further testing, You GP will discuss these results with you at a further consultation.

What is the treatment for gonorrhoea?

It would be helpful to clarify the route of administration for the injections and where they will be delivered. Including information of the length of dose and time of treatment would also be useful we also suggest the inclusion of this sentence: *It is important to have all injections and you take the full course of tablets.*

What can happen if gonorrhoea is not treated?

We suggest moving the following sentence from the section above to below this heading. *It is important to be treated to prevent complications to yourself and prevent spread of the infection, even if you have no symptoms.*

We suggest the following clarifications for the sentence below

In men, untreated gonorrhoea can cause long-lasting irritation in the penis or pain in the testicles. Infertility can occur from the scarring in your testicles.

In women, untreated gonorrhoea may cause infection in the uterus and fallopian tubes which is called Pelvic Inflammatory Disease (PID). PID can have serious effects including infertility, long-lasting pelvic pain and pregnancy in the fallopian tubes. When pregnant gonorrhoea can cause problems for both mother and baby therefore prompt treatment is always recommended.

In both men and women, untreated gonorrhoea can also cause joint infections and arthritis.

It is also important to include how quickly these complications can develop, i.e. if someone is undiagnosed for three weeks is this long enough to cause these serious side effects?

Do sexual partners need treatment?

In this section the second sentence is unclear, should current partners be treated regardless of your test results and symptoms or their own? The last sentence could also include whether partners from the last two months require treatment as well as testing.

When can I have sex again?

The last sentence of this section could be amended to read: *It is recommended that you do not have vaginal, oral or anal sex for seven days after starting the antibiotic treatment.* It would be good in this section to include information here on how this relates to the length of treatment and dose of antibiotics.

How do I avoid getting infected again?

The second dot point needs some clarification as it is unclear whether use of a condom for oral sex is important, context is needed.

Where can I get tested and treated for gonorrhoea in Canberra?

We suggest using the Find a Health Service website as the link under the heading General Practitioners (GPs) in Canberra.

Cryotherapy After Care

This sheet was slightly confusing to provide feedback for as many were unsure as to whether this related to genital warts. Some consumers who provided feedback commented that if this was for genital warts they would have liked a lot more information on this. A further sentence could be included in the introductory paragraph explaining what cryotherapy is to provide a context for the use of liquid nitrogen. This could possibly be reworded as follows: *Cryotherapy is a technique undertaken in the clinic rooms which uses liquid nitrogen to treat warts and some other skin lesions. Liquid nitrogen works by rapidly freezing the wart or lesion*

causing damage to cells in that area, and destroying any warts or lesions treated. It is important to look after the treated skin area following cryotherapy.

A further heading below the introduction could read ***Timeline for After Care***

Day 1 following treatment:

When discussing the development of blisters clarification on what is 'too large'. It would good to discuss pain relief and possible use of dressing under this heading.

Days 2 and 3 following treatment:

A clarification of what *weepy* means in this context would be useful, it is also important to provide a context for the word *mild* what constitutes mild symptoms. In terms of *not covering the area too closely* an example (i.e.no tight fitting underwear ect.) would be useful. Including a salt to water ratio for someone running a bath would also be useful.

Days 3 to 4 following treatment:

The last sentence states that after two weeks it should heal, if this doesn't occur what action should be taken?

Genital Herpes

In the introductory paragraph it may be useful to include the areola and nipple as a possible place for blisters. Including information as to which virus is associated more closely with genital herpes would also be useful along with an explanation that not everyone with cold sores will develop genital herpes

Primary infection

This heading could be amended to read *Primary or intital infection*.

The dot point referring to vaginal discharge does not need the 'in women' to be included. The last dot point could be clearer if where aches and pains can be expected was stated.

Recurrent infections

For this section the main feedback received stated that the specifics of the immune response and the role antibodies play is unnecessary information at this stage

How is herpes diagnosed?

In this section it would be helpful to include a description of if the collection of the fluid from the blister, how is this done? Is it painful? How long until results are given?

How does someone get infected with herpes and how common is it?

The use of the HSV virus and genital herpes needs to be consistent throughout the document, especially given this refers to both cold sores and genital herpes. It is also important to make clear if having sex with cold sores can give someone genital herpes. In the second sentence it is important to state this usually occurs during *unprotected sex*. Many consumers who commented also stated that how common the virus and the epidemiology regarding Australia's rates of infection did not seem relevant or useful to them.

How can the chances of transmitting HSV infection to a sexual partner be minimised?

We suggest changing the above heading to *How can I protect my sexual partner contracting genital herpes?*

Living with genital herpes

Further feedback from those consulted also suggested including a heading like the one above like to include information about how to avoid outbreaks, and the importance of discussing this condition with sexual partners.

HIV Testing

It is important that this fact sheet addresses the fact that HIV testing can be frightening and that testing positive can be very scary. Including information about emotional well-being and support is essential.

What is HIV?

In this paragraph a further sentence describing how untreated HIV can lead to AIDS would be useful.

What does a positive HIV test mean?

We suggest moving this section above what does a negative HIV test mean. We also want to reiterate how important it is to address possible fear at getting a positive HIV result and where to get support.

Genital Skin Care

We suggest rewording this introductory paragraph as follows:

Genital skin is very delicate and more prone to irritation than other skin on the body. Poor skin care can result in dry, itchy, irritated skin, which may increase the risk of skin infection in your genital area.

In this section it would also be useful to be more specific what area are you talking about, internal, external, or the general area? Is there area and symptoms different in men and women?

Cleansing

We suggest changing this to *Cleaning*.

Products to avoid

It is unclear if this section is prevention of irritation or treatment for when irritation has occurred, it would be useful to clarify this.

Dot point four refers to '*feminine*' products an example would be useful or being more specific here. Dot point eight suggests avoiding the use of pads and panty liners, this will be impossible for some woman and not comfortable for many others, perhaps advising people to change pads and panty liners regularly and avoid scented products would be more appropriate. The second last dot point uses the term *intimate body sprays*, being more specific or having an example of this would be useful.

Decreasing friction or rubbing

The first dot point reads like an explanation rather than advice and could be moved up as an introduction to this section. The third dot point could be clarified to include what to use to dry skin with (i.e. a clean dry towel). It would be useful if the fourth dot point was more specific, explaining what methods of hair removal should be avoided and why. The fifth dot point could also be more specific, what clothing should be avoided tight underwear?

Care of irritated or burning skin

Several consumers suggested including a section on care of irritated or burning skin would be useful. As mentioned earlier, consumers we consulted for comment were extremely positive about this particular fact sheet and felt it should be more widely distributed.

In conclusion, we are pleased to provide feedback on these brochures and look forward to reading more in the future. If any aspect of this response requires clarification please contact Eleanor Kerdo by email eleanorkerdo@hcca.org.au or by phoning the HCCA office on 6230 7800.

Yours sincerely,



Darlene Cox
Executive Director
Health Care Consumers' Association

