

APPENDIX 3- FOCUS GROUP DISCUSSION GUIDE
(LGBT inc MSM or WSW)

Date _____
Interviewer _____
Town/District _____
Organization/Facility/Care setting _____
Venue _____

Demographic information (to be collected on attendance sheet):

Tribe _____
Name/Pseudonym _____
Age _____
Gender _____
Sexual identity _____
Relationship status _____
Primary diagnosis if any _____
Time since diagnosis if applicable _____

Language(s) _____
Time began _____
Time ended _____

Group introductions:

Please introduce yourselves briefly. We will also pass around an attendance sheet at the end of the discussion to capture your details for our research.

Guiding questions

Health management:

- In your experience what serious illnesses do you think are most common with LGBT/MSM?
- What are your thoughts on HIV/AIDS as a life-threatening illness? How important is it to you to be tested for HIV? If you have been tested for HIV, what motivated you to be tested? Have you changed any behaviors since? How easy/difficult has that been?
- Can you tell me where members of your community receive care for a serious illness? (e.g. Primary, secondary, tertiary care)
- How do you learn about updated developments in HIV/AIDS and cancers and their treatment?
- How do you access health services to manage cervical/anal cancer checks, STI and OI treatments and/or ART provision?
- For members of your community living with a life-threatening condition what do you think would be their main needs and problems? (PROMPT: physical, psychological, social spiritual)
- What has been your experience of how health providers help manage any physical, emotional, social or spiritual problems that your colleague or their family may encounter from a diagnosis of a life-threatening condition?
- If you or any of the LGBT community was seriously ill and in pain, how would you access pain medications?
- Has any health provider ever discussed palliative care with you?

Exploration of Sexual Identity:

- As someone who identifies as X, in what ways do you think your experience of your illness might be different to people who identify as heterosexual?
- How about your experience of care, how might that have been different?
- When you are with your health care providers, (doctors, nurses, and other members of the health care team) do any of them know your sexual identity?
 - YES....how?

- NO....why?
- Is this how you prefer it to be?
- How do you feel about being asked directly about your sexual identity?
- Should you be asked directly by the health care providers, or should it come from you first?
- What kinds of things make it easier/less easy to let health care providers know your sexual identity? (PROMPT: communicative, environmental, societal, institutional)
- Has the gender of the health care provider been relevant in disclosing your sexual identity? Do you experience different care from male or female nurses and doctors?

Communication and Sexual Identity:

- When taking your personal history or talking to you during appointments, do health care providers ever refer to your sexual identity? How do they do it....WELL/BADLY?
- Do you feel they respect and understand your identity? How do they demonstrate this?
- Are there phrases or words that the health care providers have used that made you feel more able to talk about your sexual identity?
- How about in terms of the way they talk to you – their manner, body language?
- Do you find the health care providers use the same words to describe sexual identity as you?
- Can you tell me about when the issue of your sexual identity hasn't been handled well?
- Are there phrases or words used by the health care providers that make you feel uncomfortable about sharing your sexual identity?
- Have there been times when their manner or body language has stopped you sharing your identity? How?
- How would you like your sexual identity to be acknowledged and referred to by the health care providers?

Involvement of Partner: (IF THEY HAVE PARTNER/EQUIVALENT)

- Has your partner or family attended appointments with you?
- Do you want them present?
- Have you felt they would be welcome?
- Can you tell me how they are acknowledged by health care providers?
- Have they talked about what the experience was like for them?
- Would you like it to be any different? How?
- Do you feel your partner/family have enough support?
- What forms of additional support would be useful for them?

Support Structures:

- When you get ill, or are in pain or your symptoms make life hard, what do you do? Who do you turn to first?
- Where do you get your support from? (PROMPT: partner, family, communities, institutional)
- Are they known to your health care team? How/why?
- Who would you say are your main sources of care? (outside of professional services like doctors nurses and social worker). (PROMPT: CAREFULLY PROBE FOR BIOLOGICAL VS CHOSEN FAMILY AND NETWORKS)

Planning for Future Care:

- Looking forward, if your health changes and decisions need to be made about how best to care for you, who would you like to be involved?
- If you were to be diagnosed with a life-threatening illness such as cancer, what health care and support do you think you could expect to receive for the rest of your life?
- If you were to reach the end of your life due to a serious illness, what you want to happen?
- Do you think this will be done? Can you see any problems?
- Have you had this discussion with anyone? Would you like to, and with whom?
- Do you have someone who could arrange this?

Reflections and Recommendations:

- When you discuss you, your life, and what matters to you with your health care providers, do you think your sexual identity should be part of that discussion? Why? How?
- Do you have any questions that you think you'd like to ask your health care providers but don't?
- Are there questions you feel the health care providers don't ask you?
- In your experience how does your sexual orientation affect your access to health care?
- Has any health provider ever discussed palliative care with you?

The aim of our study is to help make LGBT and MSM people know that they and their partner or significant others can expect good care when they have a serious illness, but also to help health care teams to provide better care.

- What should we teach health care providers?
- What things do you think are important for us to tell the LGBT and MSM communities about living with life-threatening illness? (PROMPT: are there barriers or facilitators to care that we need to explore/highlight)
- What do you think would be the best materials / media to share our findings?
- If there was one thing that we could change, what would be most important to you?
- Is there anything you'd like to add?