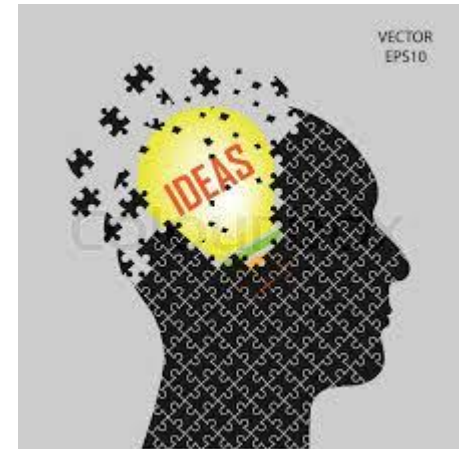


# Setting up a large trial in MSM: lessons learned

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# Introduction

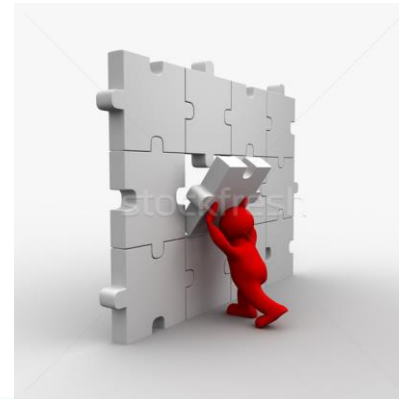
- MeCRU clinical trials unit is set up in the SMU
- Vision to contribute to science as it develops community
- Our capacity to do clinical trails built since 2006
- Leadership is by a site PI with other investigators and managers.
- Responded to a perceived need of MSM in our community



# Project definition

## Research aim

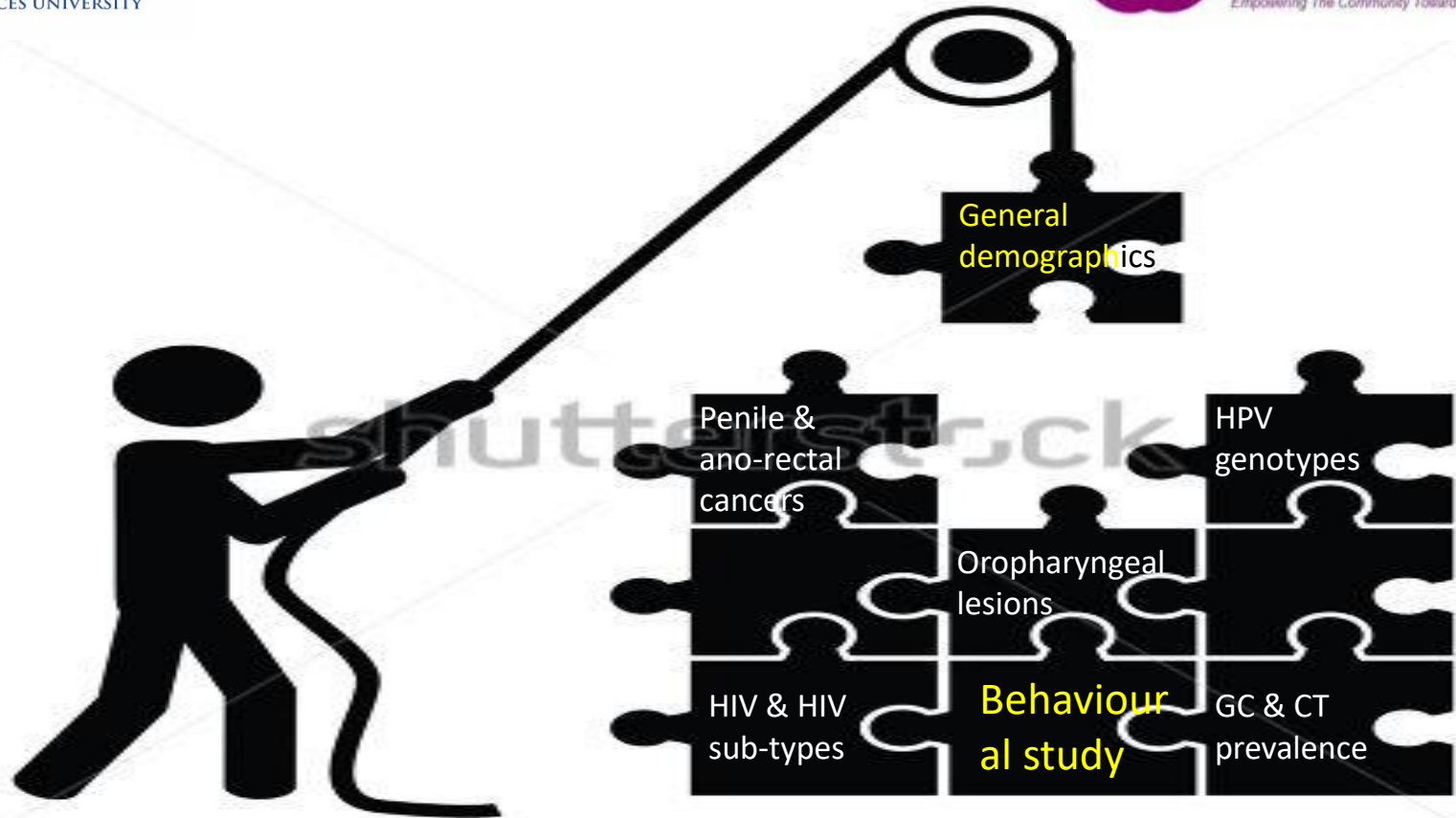
- To determine the prevalence, types and factors associated with HPV related precancerous and cancerous lesions, HIV and other STIs in the MSM population residing in the North West of Pretoria.



# Project definition

## Specific objectives

- To determine the **prevalence** of STIs, HPV and the common HPV genotypes circulating amongst MSM living in the area North West of Pretoria.
- To determine the prevalence and type of penile, ano-rectal and oropharyngeal precancerous and cancerous lesions.
- Determine the HIV and HIV subtypes prevalence amongst the population of MSM in the area.



Arms of investigations in the MSM study at MeCRU, Pretoria.

# What is a lesson?

- Defined as a period of learning
- or
- A structured period of time where learning is intended to occur
  - Looking back, what did we learn?

# Areas of learning: Lesson 1

1. **Birthing the idea** requires you to think beyond your own competence because its not about you: lab work, post graduate students, funding sources, the community, project leadership, co-workers, research community experience, location of the project, publications, collaborators etc.





# Lesson 2

## 2. The research site has to be prepared.

**LGBTIQ** issues have a tendency not to sit well with people who are not part of this community. Sexual minorities quickly manifest the insecurities of others. MeCRU staff underwent training. Some definitions: top, bottom, after nine, fisting, etc. What I subsequently learnt...

# Lesson 3

3. The study needs to **add value** to the specified community.

A gate keeper who is an organizer of the gay community in our area decided to stop them from coming to site through misinformation. This had to be dealt with specifically. It does not help to ignore the problem.

# Lesson 4

**4. Understand your study population.** It soon became clear to us that this group of sexual minority is generous with their contacts and partners. They have no fear of sharing information with each other where they stand to benefit.

We used the **snowballing technique** for participant recruitment and it worked.

# Lesson 5

5. The **study design and methods** should fit what you intend to investigate. We had included a local anatomical pathology analysis of the rectal swabs.

Some of the sections of the work were qualitative whilst others were quantitative. Because of the range of people involved we were able to have good variety of what was investigated.

FOMO

# Lesson 6

## 6. A strong coordination role is critical.

Reports of the study may be of a range of depths in specific fields. The role of each specialty involved should be harnessed for maximum contribution.

*Its not about you but the science*

# Lesson 7

7. Agreement on **authorship** should be decided early in the investigation. As a team there should be agreement on contribution leading to acknowledgement.

Whose is the **data**? Team work means corporate ownership.

# Lesson 8

8. Always look for **the difference it will make in clinical practice**. What we needed to do for our participants challenged our health care services. The way forward is difficult.

Demand for sex change operations.

No department willing to follow up anal and penile lesions.

# Observations

- Not early birds
- Mobile
- Individual yet labelled different and by group
- Different groupings within the group
- Prefer straight men: women are competition
- Sex is a central piece in their day to day life
- Can't tolerate isolation; positive energy
- Generous with information about their circles
- Don't mind sharing sexual partners
- Looks are important



# What has become apparent?

- More work needs to be done as this study scratched the surface;
- Resources for the work should be mobilized further;
- Health care service providers need to introspect their own values;
- There is a need for proctologists and clinicians interested in managing the health of MSM.



# What are the gaps?

- **Research that meets** a need is always welcomed.
- There are **no services for gay men** in the area north of Pretoria (this includes research).
- Stigma, discrimination, prejudice and physical violence are their daily **reality**. This study held promise in that to some degree they could be examined and referred for treatment without being judged.

# Acknowledgements

- SMU as an institution
- MeCRU staff
- Research partners: virology, microbiology, anatomical pathology, oral pathology
- The MSM community in the area
- VLIR project