

Promoting Consumer Awareness and Reducing Myths Around Clinical Trials at Grampians Health

Presenter: Lisa Bell
Clinical Trials Coordinator

VCCC Intern 2021

Clinical trials medicine is good medicine

- Access to cutting edge medicine
- Clinical trials patients usually live longer and have reduced mortality¹
- Supports research for future treatments



1. Canadian Partnership Against Cancer. 2016. *The 2016 Cancer System Performance Report*. Toronto: Canadian Partnership Against Cancer

Grampians Health Ballarat

About our clinical trials unit

Clinical trials unit with approximately 80 open clinical trials

- Sponsored investigator initiated and registry
- Oncology, cardiology, neurology, infectious diseases, Gastroenterology, ICU, anaesthetics
 - Phase I to IV trials



Grampians Health Ballarat

About our community



Less linguistically diverse population

- 4.6% born in a non-English speaking country
- 3.8% speaking a language other than English at home
- Highest levels of **volunteering** in the state
- Lowest fruit and veg intake, poor GP attendance and highest (41%) of people over 75+ living alone

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“Are we just lab rats?”

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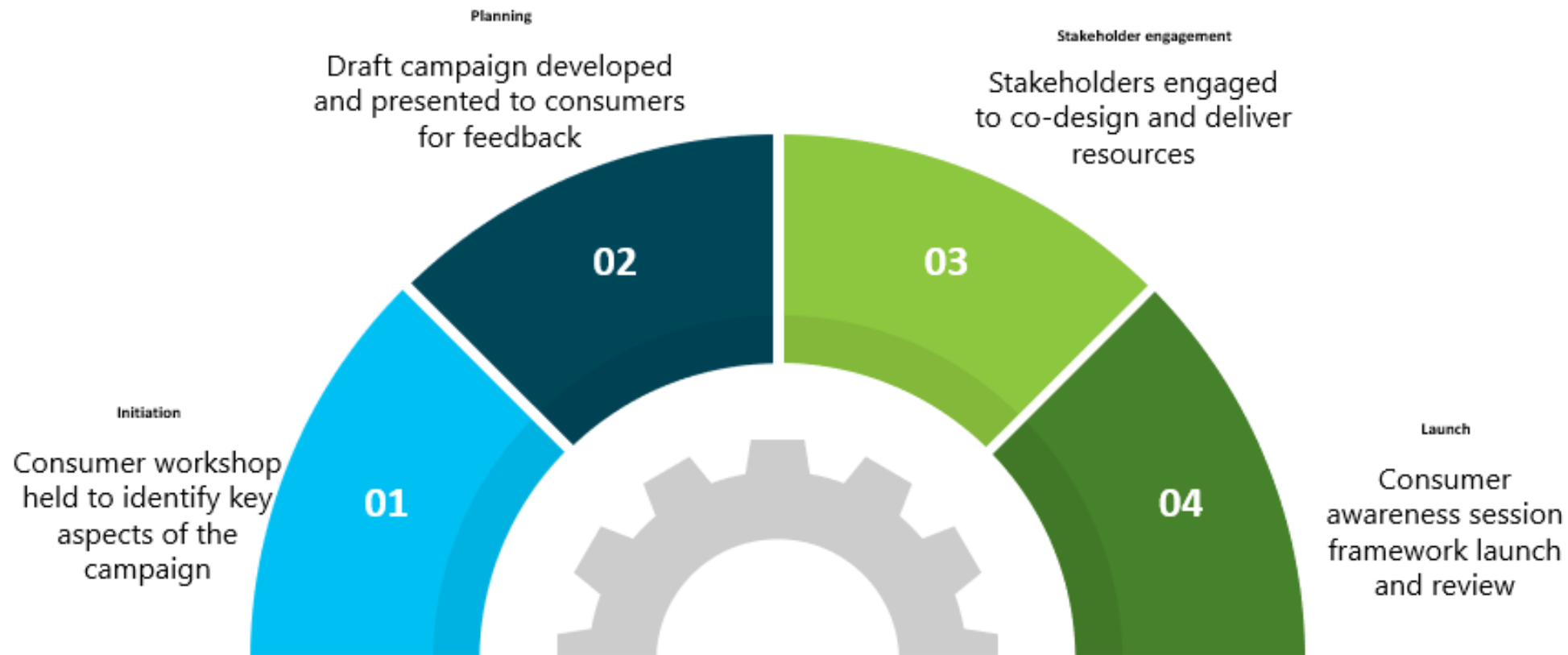


“Are we just lab rats?”

“Do we have to travel to the city?”

Project process

Consumer led clinical trials awareness campaign



Who

- Have someone who works in clinical trials (clinical trial nurse or researcher)
- For various communities (e.g. CALD), someone who is a local leader creates more trust is important. Suggestion of a local community member as an 'MC' role or ask them to attend or assist in promotion.

What

- What is a clinical trial/de-mystify?
- Types of trials
- Where you find out about clinical trials/availability of trials
- Who can participate/eligibility for a clinical trial?
- Safety of a clinical trial
Cost and time
Having a consumer's experience/perspective of a clinical trial

Where

- Important to hold a grass roots campaign in a local familiar environment.
- Some locations suggested include:
- Community centres/local government
 - Wellness centres
 - GP clinics
 - Town Hall
 - Library

How:

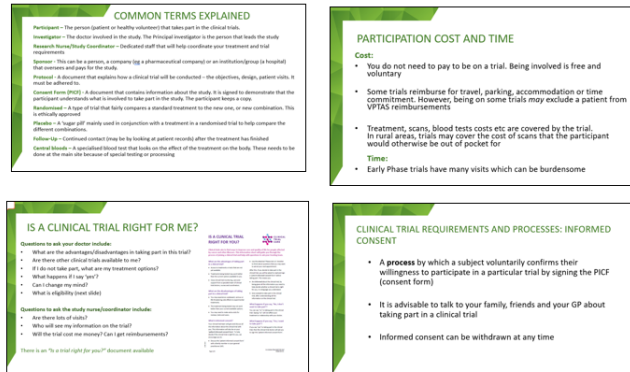
- Hybrid options

Who

- **Principle Investigator**
Dr Wasek Faisal
- **Study Coordinator**
Lisa Bell

What

Presentation slides co-created with stakeholders and consumers



COMMON TERMS EXPLAINED

Participant - The person (patient or healthy volunteer) that takes part in the clinical trial.
Investigator - The doctor involved in the study. The Principal Investigator is the person that leads the study.
Responsible/Study Coordinator - Individual staff that will help coordinate your treatment and trial requirements.
Sponsor - This can be a person, a company (eg pharmaceutical company) or an institution (eg hospital) that controls and pays for the study.
Protocol - A document that explains how a clinical trial will be conducted - the objectives, design, patient rights, it must be approved.
Consent Form (PICF) - A document that contains information about the study, it is signed to demonstrate that the participant understands what is involved in taking part in the study. The participant gives a **consent**.
Randomised - A type of trial that fairly compares a standard treatment to the new one, or new combination. This is usually compared.
Placebo - A sugar pill usually used in conjunction with a treatment in a randomised trial to help compare the different combinations.
Follow-up - Continued contact (you be by looking at patient records) after the treatment has finished.
Control Results - A comparison (often one that takes on the effect of the treatment on the body. These needs to be done at the start (the baseline) before or concurrently.

PARTICIPATION COST AND TIME

Cost:

- You do not need to pay to be on a trial, being involved is free and voluntary
- Some trials reimburse for travel, parking, accommodation or time commitments. However, being on some trials may exclude a patient from VITAS reimbursements
- Treatment, scans, blood tests costs etc are covered by the trial. In rural areas, trials may cover the cost of scans that the participant would otherwise be out of pocket for

Time:

- Early Phase trials have many visits which can be burdensome

IS A CLINICAL TRIAL RIGHT FOR ME?

Questions to ask your doctor include:

- What are the advantages/disadvantages in taking part in this trial?
- Are there other clinical trials available to me?
- If I do not take part, what are my treatment options?
- What happens if I say "no"?
- Can I change my mind?
- What is eligibility (over 18s)?

Questions to ask the study nurse/coordinator include:

- How long will it last?
- Who will see my information on the trial?
- Will I be kept and not respect? Can I get reimbursements?

There is an "is a trial right for you?" document available.

CLINICAL TRIAL REQUIREMENTS AND PROCESSES: INFORMED CONSENT

- A process by which a subject voluntarily confirms their willingness to participate in a particular trial by signing the PICF (consent form)
- It is advisable to talk to your family, friends and your GP about taking part in a clinical trial
- Informed consent can be withdrawn at any time

Where

Rotary club dinner meeting



How: Face to face

Organising the pilot

Slow and steady wins the race

- ✓ Thorough consumer consultation takes time
 - ✓ Use your local network
 - ✓ Unexpected delays and changes to plan
 - ✓ Keep it simple
-



What we learned on the night

- ❖ Personal connections mattered most
- ❖ Adaptability of resources essential to make the presentation 'our own'
- ❖ Socialising with the audience was just as helpful – *and a key source of feedback*

- ❖ From small things big things grow
- ❖ QR codes to feedback surveys were not completed by the majority of attendees



Thank you!

Jessica Freeman



Duncan Colyer



Eleanora Kay



Lea-Anne Harrison

Carmel Goss

Rebecca Gurnett

Wasek Faisal



Amanda Clifford



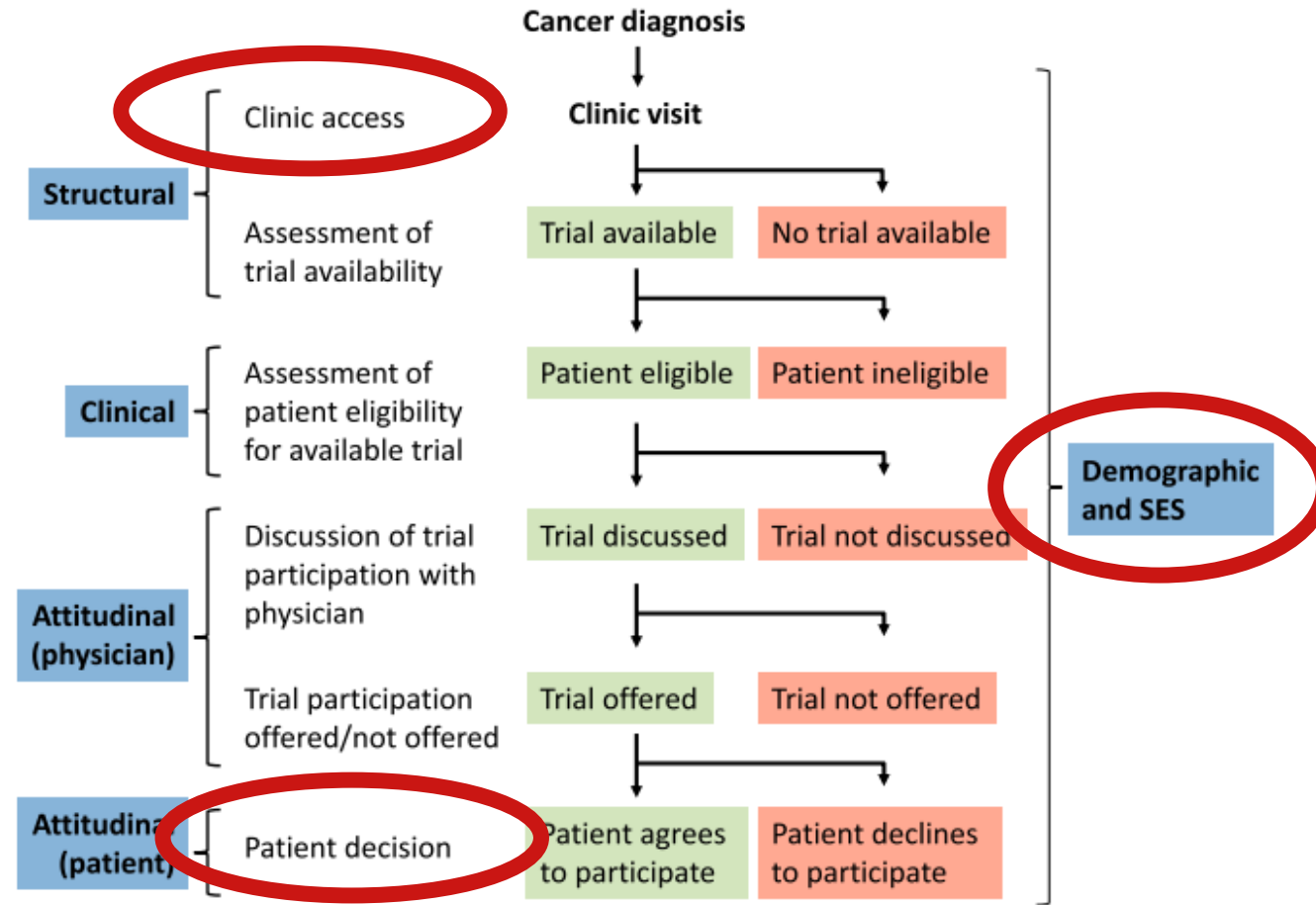
Kathleen Wilkins



Wendy Benson

Determinants of participation

- Trial participation differs according to demographic and socioeconomic factors
- Clinic access can be challenging for regional and rural patients
- Patient decision and willingness to participate in clinical trials is **critical**



Abbreviation: SES, socioeconomic status.