

Ensuring meaningful community engagement in research studies: GPP and Lessons Learnt

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Aims of this session

- Discuss GPP and how to conduct meaningful community engagement to benefit both researchers, participants, and communities.
- Participate in exercises to examine how we can contextual our research within broader SRH and HIV health issues
- Use examples and case studies to deepen our understanding of stakeholder engagement, including focus on:
 - Effective and creative ways to do community outreach for recruitment and retention,
 - Ways that sites can utilise CABs effectively,
 - How GPP can improve how we run our research studies

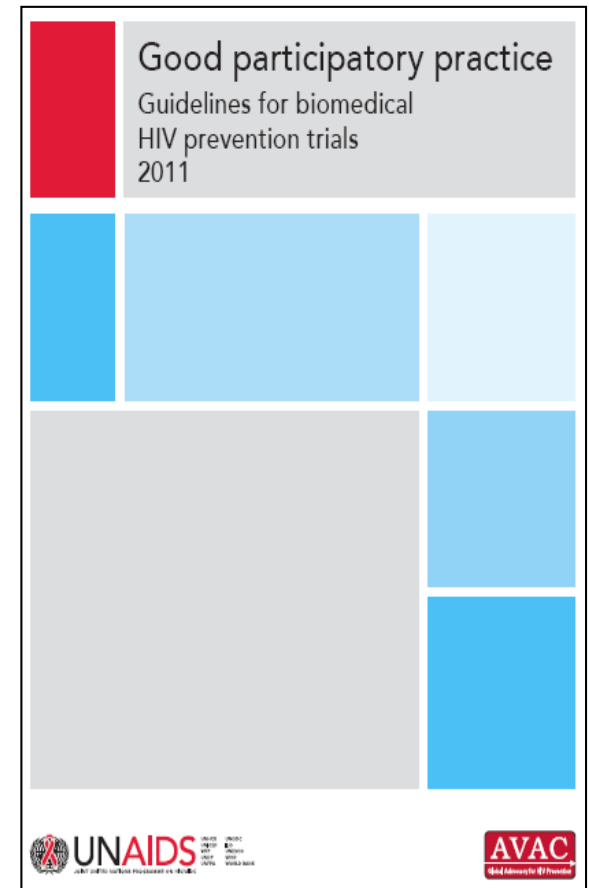
Brief History of Community Engagement in Research



What are the GPP guidelines? What makes them different?



- Provides a formal approach to stakeholder engagement
- Provides useful methodology and guiding principles for stakeholder engagement at all levels
- GPP tools and trainings enable researchers and trial sites:
 - to proactively plan and budget their stakeholder engagement (not just react)
 - Implement activities strategically
 - Review, monitor, and revise strategies as needed



Using GPP to strengthen community engagement and improve our research:



Unpacking Community engagement



Who is the “Community”?

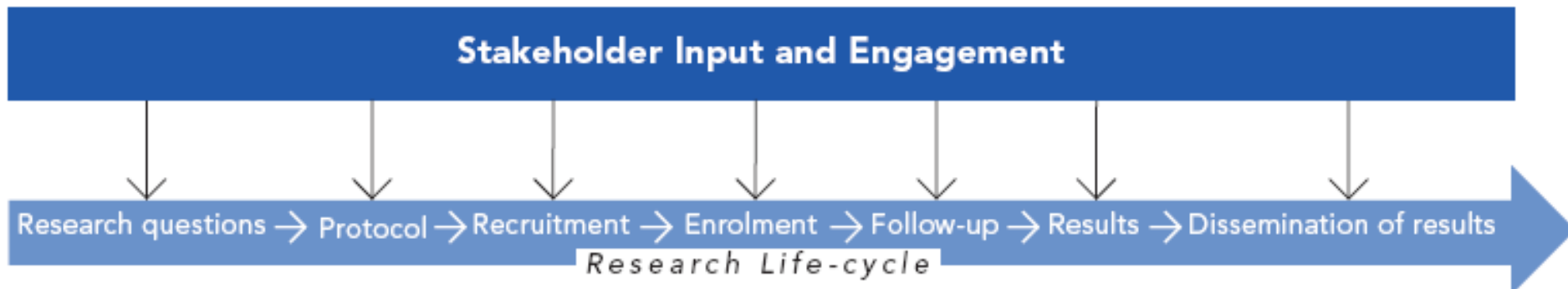
- The Good Clinical Practice Guidelines define a community as “separate and overlapping groups of people who are either infected or affected by HIV and other illnesses/diseases in various ways
- GPP defines community stakeholders as “individuals and groups that are ultimately representing the interests of people who would be recruited to or participate in a trial, and others locally affected by a trial.”



What is “Community Engagement”?



- A process through which funders, sponsors, and implementers build meaningful relationships with stakeholders.
- Its goal is to shape the research process by using the expertise of stakeholders.
- It is *not* recruitment....but good stakeholder engagement can



ACTIVITY 1: “Write and squash”



In your context
(local research site/community):

1. What makes community engagement “meaningful”? Be specific.
2. In thinking about your answer to #1, what challenges do you/your team face to achieving meaningful engagement?

Activity 1: DID WE COVER? Community Engagement Challenges



- Despite efforts to standardise community engagement via GPP, it is often implemented in a fragmented manner
- GPP is often misunderstood, or interpreted differently by different researchers, sites and studies.
- Some believe that communities do not have capacity to consume complicated scientific, clinical and ethical aspects of HIV and health research.
- Funding community engagement activities remains a challenge, and often results in ad-hoc or inconsistent engagement with communities.

Contextualising community outreach, recruitment and retention activities



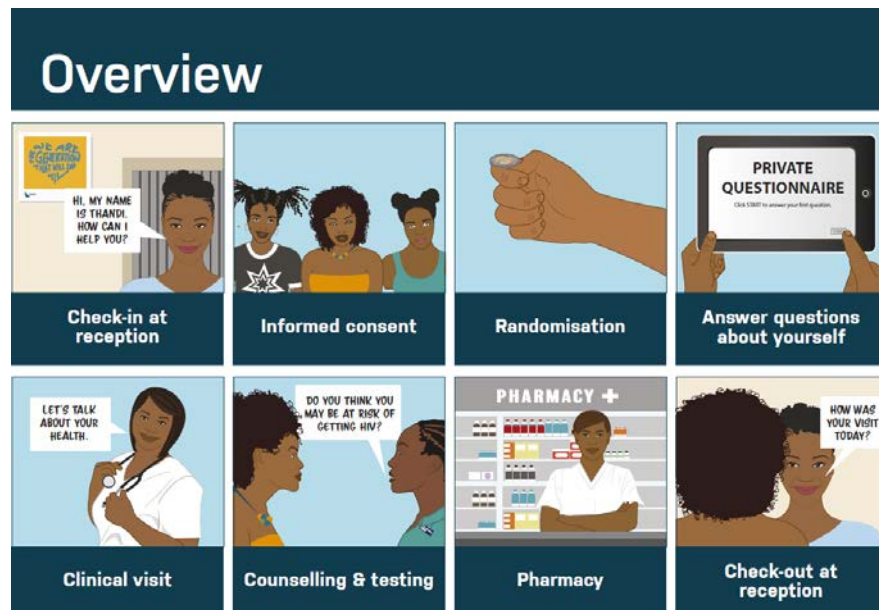
#1 Put community education at the heart of every activity and event.



Contextualising community outreach, recruitment and retention activities



#2 Research literacy involves translating scientific jargon into everyday language and images that people can relate to.



05 Clinical visit (continued)				
Activity		Screening	Enrollment	Follow-up
Discuss family planning and contraception options		<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Receive study products			<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>

Contextualising community outreach, recruitment and retention activities



#3 Forge strategic partnerships with key stakeholders.



ACTIVITY 2: Using context



Using Holidays & National Health Calendars serves to:

- Locate the study within broader SRH and HIV prevention issues;
- Leverage partnerships with local groups in support of effective recruitment and retention activities;
- Contribute towards setting an advocacy agenda on issues related to the study; and
- Educate the community on issues, such as social behavioural change, risk perception, etc.



Case Study – the ECHO Study

WORLD CONTRACEPTION DAY

26 SEPTEMBER 2017



PREGNANCY
SHOULD
BE BY **CHOICE**
NOT BY **CHANCE**

Do you **KNOW** your **OPTIONS**?
visit: www.yourlifenow.co.za

University of the Witwatersrand
WITS RHI

PROTECT YOURSELF

Did you know...?

Family planning methods prevent unwanted pregnancies.

The correct and consistent use of condoms prevents STIs and HIV.

Benefits of condom-use:

- 1 Condoms are the only contraceptive method that also protects against STIs including HIV.
- 2 Consistent and correct use of condoms can be very effective for contraception.
- 3 Using condoms AND another family planning method offers more protection from pregnancy than condoms alone.

Contact your local Echo site for more information about family planning and protection against HIV.

echo
Evidence for Contraceptive Options & HIV Outcomes

ACTIVITY 2: Using context cont.



SEPTEMBER 2017						
MON	TUE	WED	THU	FRI	SAT	SUN
				1	2	3
4	5	6	7	8	9	10
11	12	13	14	15	16	17
18	19	20	21	22	23	24
25	26	27	28	29	30	

Events	Notes:
International Women's Day, International Contraceptive Month.	

OCTOBER 2017						
MON	TUE	WED	THU	FRI	SAT	SUN
						1
2	3	4	5	6	7	8
9	10	11	12	13	14	15
16	17	18	19	20	21	22
23	24	25	26	27	28	29
30	31					

Events	Notes:
Breast Cancer Awareness Month.	

NOVEMBER 2017						
MON	TUE	WED	THU	FRI	SAT	SUN
		1	2	3	4	5
6	7	8	9	10	11	12
13	14	15	16	17	18	19
20	21	22	23	24	25	26
27	28	29	30			

Events	Notes:
16 Days of Activism.	

DECEMBER 2017						
MON	TUE	WED	THU	FRI	SAT	SUN
				1	2	3
4	5	6	7	8	9	10
11	12	13	14	15	16	17
18	19	20	21	22	23	24
25	26	27	28	29	30	31

Events	Notes:
16 Days of Activism continues, World AIDS Day.	

Working in pairs, choose a holiday or health calendar day (Oct-Dec) to:

- Develop an activity for one of your current or planned studies.
- Decide on aims and possible partners.
- Address how it will relate to the health day you've selected.

Unpacking Community Advisory Boards (local and global)



CAB: Roles and Responsibilities

- Share questions and voice concerns from the communities and study participants about research studies.
- Review protocols , ICFs and advise on participant materials.
- Provide input on GPP, recruitment and retention strategies.
- Ensure materials are acceptable & culturally sensitive.
- Disseminate study information to local communities.



DISCUSSION: How GPP can help strengthen the effectiveness of CABs

- Establish formal Terms of Reference to ensure commitment and understanding of roles and responsibilities by all parties
- Templates to standardise and improve documentation of discussions and input
- Track on GPP plan WITH CAB – make them partners in the process
- Train and empower CAB members to be spokespeople and ambassadors for your research, not just recipients of information
- Monitor invites and links between CAB members and sites. Measure success wherever you can.

Making our research centres/sites community friendly

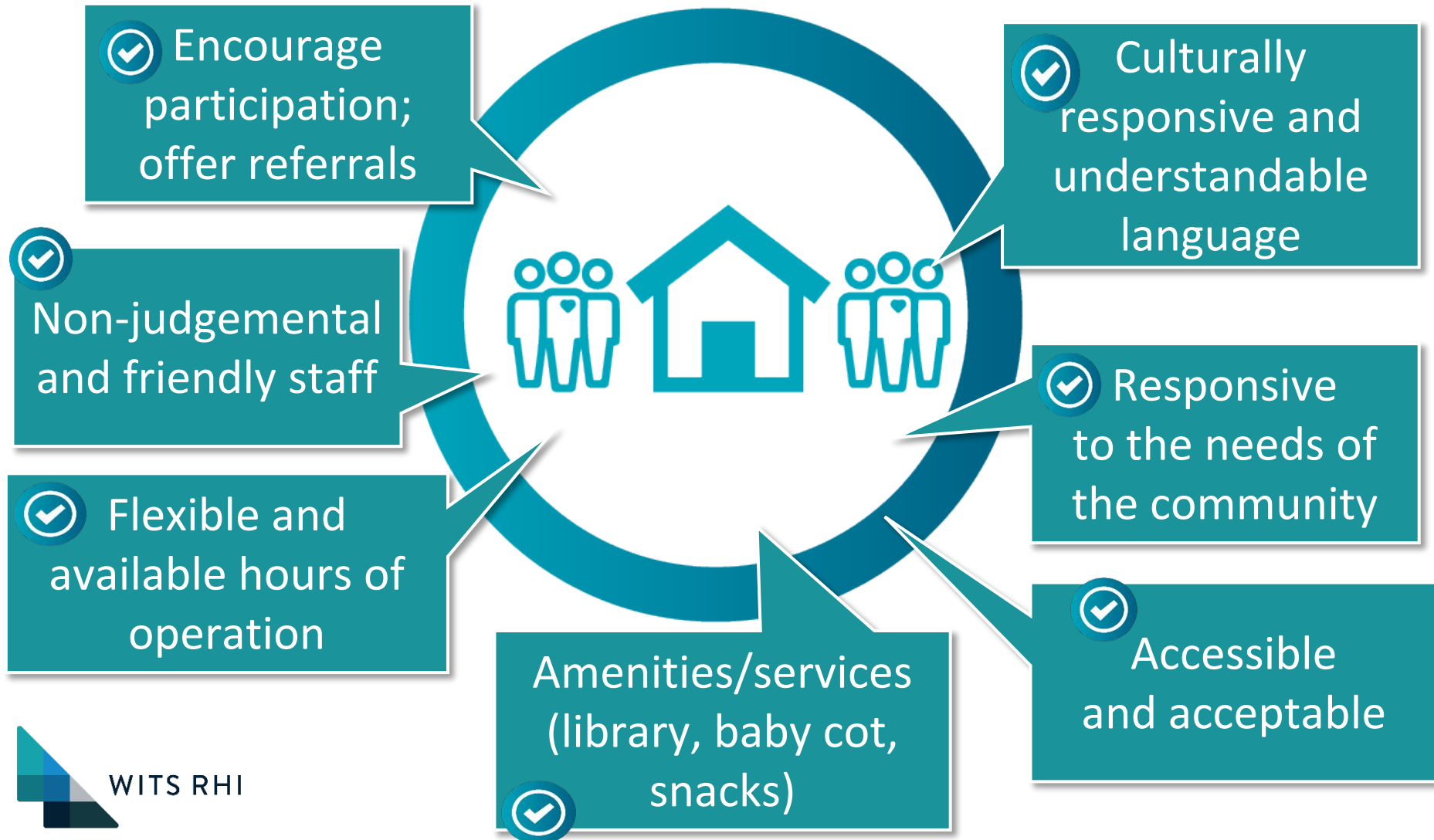


Background



- Myths and rumours about research still prevalent
- Community members may feel unwelcomed in research centres
 - E.g. Use of technical terms and scientific language that communities lack confidence on may intimidate people
- Ongoing need for continuous research literacy and community education is often neglected, and this can disempower communities and create distrust between research centres and communities

What makes a research centre “Community friendly”?



It takes resourcefulness, not necessarily resources



- Often a few small adjustments can make a big difference in HPTN Studies.
 - E.g. At RHI, we got books donated from Rotary to start libraries at each clinic/site.
 - Have mini-crèche with child-minder to watch babies while women at visits (e.g. 081 infusions take long and childcare can limit availability to make visit)
- This will contribute towards meaningful study participation and retention.



ACTIVITY #3 BRAINSTORM



Thinking about your site, brainstorm 1-3 specific actions you/your team could do to make your site more community friendly?

Summary: Implementing GPP requires buy-in and pro-active commitment from everyone



THANK YOU!

