

JOINING UP THE DOTS: the links between violence against women, HIV and achieving our sexual and reproductive health and rights: the need for the ALIV[H]E Framework

Presentation prepared for UNAIDS

*Based on presentations made at STOPAIDS, London and
RCOG, London, June and July 2017*

October 2017

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ON THE RIGHT(S) TRACK

JOINING UP THE DOTS: the links between violence against women, HIV and achieving our sexual and reproductive health and rights: the need for the ALIV[H]E Framework

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- 1) Violence Against Women (VAW) and HIV**
- 2) SRH&R of women living with HIV**
- 3) The research & policy disconnect**
- 4) The current formal research paradigm**
- 5) Strengthening and expanding the
evidence base: the ALIV[H]E Framework**



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1) The first two links to explore are
between violence against women and
HIV

**Violence Against
Women**

HIV



PREVALENCE →

1 in 3 women

throughout the world will experience physical and/or sexual violence by a partner or sexual violence by a non-partner



HEALTH IMPACT: Women exposed to intimate partner violence are →

Mental Health

TWICE 
as likely to experience depression

ALMOST TWICE 
as likely to have alcohol use disorders

Sexual and Reproductive Health

16% 
more likely to have a low birth-weight baby

1.5 TIMES 
more likely to acquire HIV and 1.5 times more likely to contract syphilis infection, chlamydia or gonorrhoea

Death and Injury

42% 
of women who have experienced physical or sexual violence at the hands of a partner have experienced injuries as a result

38% 
of all murders of women globally were reported as being committed by their intimate partners



World Health Organization

WHO Multi-Country Study 2011

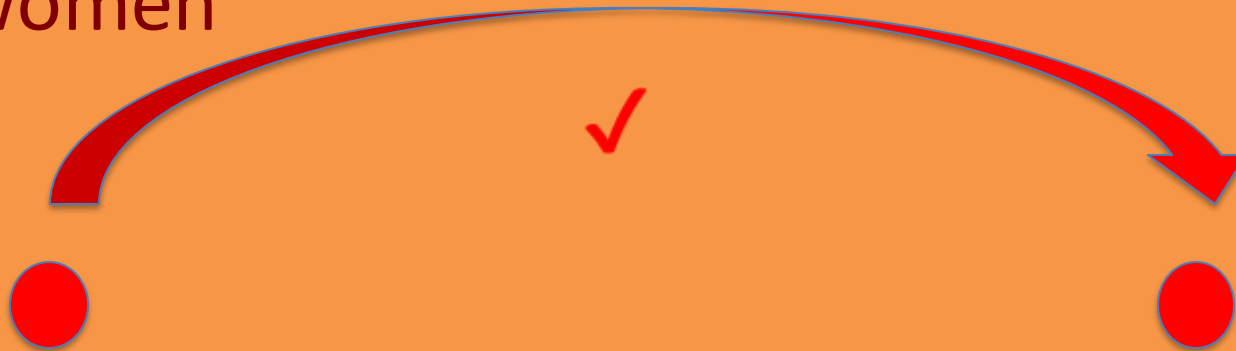
From WHO's Multi-Country Study in 2011, we know that 1/3 of women worldwide experience physical and/or sexual violence by a partner or sexual violence by a non-partner in their lifetime;

and that these women are 1.5 times more vulnerable to acquiring HIV, syphilis, chlamydia or gonorrhoea.

So we have formal evidence that
violence against women increases
women's vulnerability to HIV

Violence Against
Women

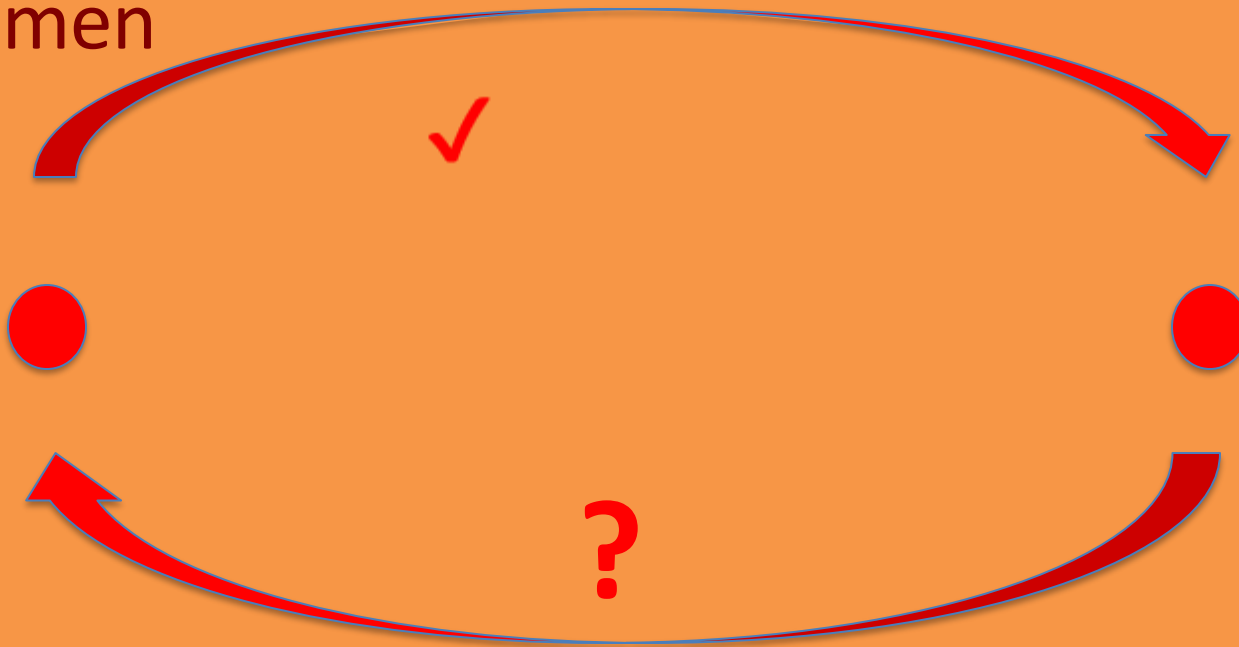
HIV



But what about whether or not the reverse is true?

Violence Against
Women

HIV



Global Treatment Access Review

In 2014, we were commissioned by UN Women to conduct a global treatment access review.

The slide below shows the story from a Focus Group Discussion of a woman from Tunisia, who experienced the shock of learning of her own and her husband's HIV after his death, followed by rejection from his family, from her own family and then also violation of her privacy by her own healthcare providers.

This is just one of many stories from around the world, which echoes the many 'anecdotal' stories from women living with HIV around the world.

We are hoping to have the findings from this review published soon in a peer review journal.

So thanks to research studies like these, we can now tick the lower arrow also.



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TRANSFORMING THE WAY WE THINK ABOUT HIV



Global Treatment Access Review

“I am living with HIV since 2007; married and I’ve got two sons. After several years of marriage, **my husband** was very ill and his health deteriorated so much, we went to the hospital and after doing lot of tests and analyses proved to us that he was infected with the **virus**, and a few days after his **death**, doctors have conducted tests for me and my sons. **I was shocked to discover my disease** and since started my journey with the torment of society that does not have mercy on the one hand and on the other hand, **his family refused to accept us, me**. It did not stop at that, even **my sister accused me of moral corruption** because of the virus and then **she and my brothers kicked me off** from my father's house, where I didn't go there since. I was also exposed to many cases of stigma and discrimination, for example; while I had to stay in **hospital** for several days, and specifically in the Department of Rheumatology the **medical team** put a banner reading: **“Beware sick with AIDS’.”**”



ATHENA



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TRANSFORMING THE WAY WE THINK ABOUT HIV

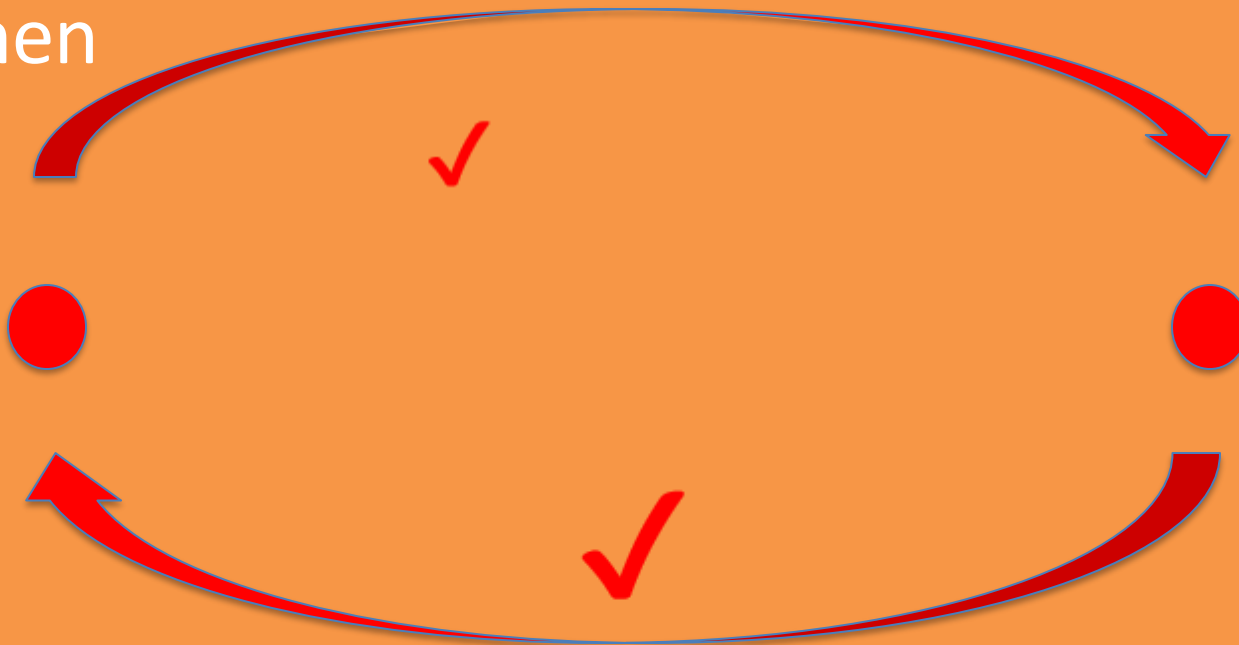


United Nations Entity for Gender Equality
and the Empowerment of Women

Violence can be both a cause and a consequence of acquiring HIV for women

Violence Against
Women

HIV



2) The next set of links to explore
relate to the SRH&R of women living
with HIV

**Violence Against
Women**



HIV



SRH&R of women living with HIV

"Building a safe house on firm ground" a global values and preferences survey on the SRH&R of women living with HIV

This informed the new WHO Guideline on this topic, published In February 2017





Consolidated guideline on sexual and reproductive health and rights of women living with HIV

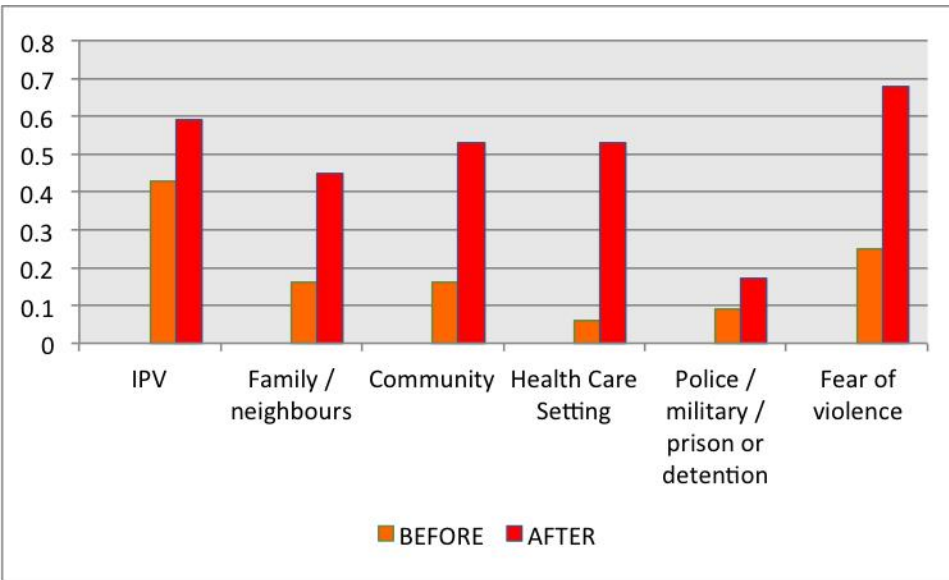


- 945 women living with HIV in all our diversity, from 94 countries, aged between 15-72, responded to the survey.
- Intended from the outset to involve women from many different regions of the world, ethnic variations, indigenous migrants, refugees, women who contracted HIV from all different routes, women from all walks of life
- This diversity was achieved thanks to the huge commitment made by our Global Reference Group.

WHO SURVEY FINDINGS

- A lot of women who responded to the survey described violence.
- Some women had not experienced intimate partner violence (IPV), pre-diagnosis, but then it started after their diagnosis.
- Some *had* experienced some IPV pre-diagnosis and it increased post-diagnosis.
- What is perhaps really shocking, though it had already been reported widely by women living with HIV in ‘anecdotal’ evidence, and in the UN Women Review above, is the *scale* of what is happening to women in health care settings.
- Before diagnosis, the level of violence against them in healthcare settings was small, after diagnosis it is high. We are very concerned about this.

Results from 58% of 832 survey respondents on Gender-Based Violence (GBV)



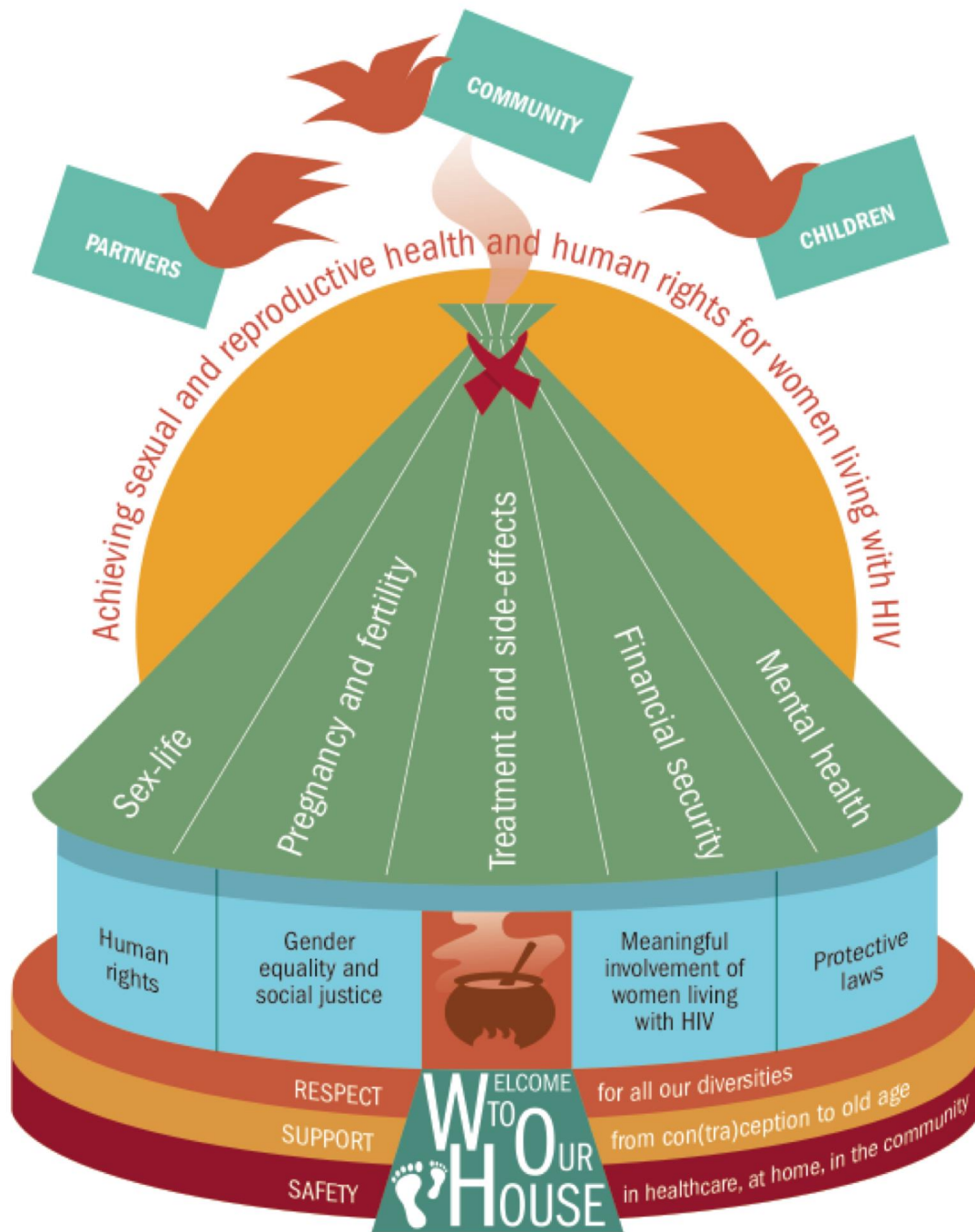
- High **IPV** levels before and after diagnosis.
- Higher levels of other violence experienced *post*-diagnosis in **health settings** & in the **community**

- **89%** reported experiencing at least one type of violence
- Experiences of violence in the health care setting often **worse** for women with *other* socially disadvantaged identities

Orza et al 2015a, [JIAS](#)



- Currently therefore, our SRH&R are *not* being achieved.
- So to illustrate our report, we created the image of “a safe house on firm ground” to represent the different components of our SRH&R.



<http://tinyurl.com/womenHIVSRHR>

THE HOUSE COMPONENTS

- An intrinsic part of the house is that it is a safe shelter. It is also made up of many separate but clearly connected components.
- At the bottom we have safety, support, and respect as key foundations.
- Then we have what makes up the strong walls: human rights, gender equality and social justice, meaningful involvement of women living with HIV and protective laws.
- Then we have different roof slates: sex life, pregnancy and fertility, treatment and side effects, financial security, and mental health.

BEYOND THE HOUSE - part 1

- Beyond the house, there is the image of the sun rising, around which it says 'Achieving sexual and reproductive health and human rights for women living with HIV'.
- Above the sun there are 3 birds holding cards saying 'partners', 'community' and 'children'.
- The principle behind the house image is that we have complex dimensions to our lives as women living with HIV: at all stages we need to look at this from lifelong perspectives and the complicated things going on in our lives.

BEYOND THE HOUSE - part 2

- It is absolutely critical that our own sexual and reproductive rights are achieved. This is, first and foremost, our own intrinsic right.
- There is also a win-win for all here. If others help us achieve our sexual and reproductive rights, then we, in turn, will *also* be able to support our partners and children and communities, which is what so many women want to do anyway.
- Just as we are all told on aeroplanes about putting our oxygen masks on first, before we help others, so it is here. If our rights are secured, then we are also best placed to support others around us.

3) Examining the disconnect between Research & Policy and women's realities

Research & Policy



Women's
realities



THE RESEARCH & POLICY DISCONNECT – part 1

- “...we conclude that erroneous justifications were initially given in support of Option B+. We identify tensions that remain in light of these results and argue that future strategies would benefit from a community-focused, human rights-based approach.” *Hodson N and Bewley S. JVE 2017; 3: [163–166](#)*
- “In this review, we found the amount of peer-reviewed literature to directly address human rights and the SRH of women living with HIV to be far more limited than expected in terms of quantity, and what does exist only addresses a few rights in the context of a few areas within SRH.” *Kumar S, et al. JIAS 2015; 18 ([Supp 5](#))*
- “Most studies placed greater emphasis on instrumental health outcomes to prevent HIV transmission than on the intrinsic well-being and SRH of women living with HIV.” *Beres L et al. AIDSCARE [2017](#); 29, 9.*

THE RESEARCH & POLICY DISCONNECT – part 2

- There is a big disconnect:
 - between policies and research, which focus on getting women on treatment as soon as they are diagnosed and getting them to ‘disclose’ to others,
 - and the realities facing many women once diagnosed.
- A woman is ‘offered’ treatment:
 - it is supposedly a choice but the way the policy has been interpreted by healthcare providers means that it is often *not* a choice.
 - to start anything on day one after a major diagnosis like this is a huge ask.
 - if women decide *not* to start treatment straight away, they’re often labelled as ‘defaulters’
 - there is a lot of blame in the language around these issues.

THE RESEARCH & POLICY DISCONNECT – part 3

- An analysis was conducted of how many times the word ‘violen’ (ie the stem of ‘violent’ and ‘violence’) appeared in the 480-page 2016 WHO Guideline on [ARVs](#), published by the HIV Department. In this whole document, the word appeared 3 times.
- The words ‘stigma’ and ‘discrimination’ appear a few more times, but still do not adequately address the numbers shown in the graph above. Moreover, these nouns do not adequately acknowledge the ‘structural violence’ experienced by women living with HIV in health-care settings, as explained in Orza et al 2015a. (See also Galtung 1969 and Farmer et al (2006).

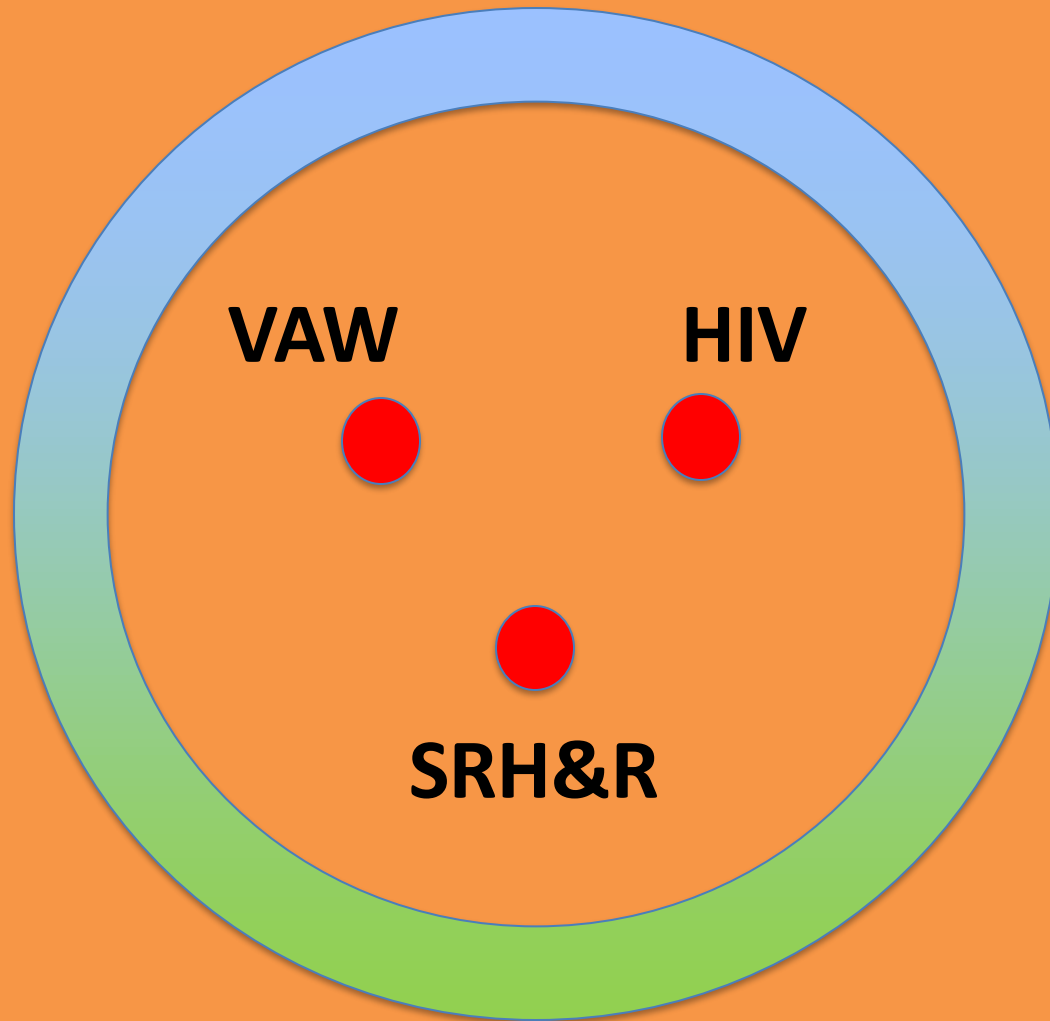
CONSOLIDATED GUIDELINE ON SRH&R OF WOMEN LIVING WITH HIV – part 1

- By contrast, this new [Guideline](#) is women-centred, based on research with over 800* women, living with HIV. It is only 1/3 of the length. It has well over 200 mentions of the word ‘violence’.
- There is therefore a disconnect between policies and guidelines such as the ARV Guideline and the realities of women’s lives as we see in the new SRH&R Guideline.
- We need to bring the 2016 ARV Guideline also into line with women’s realities and rights, to ensure safety and human rights principles.

CONSOLIDATED GUIDELINE ON SRH&R OF WOMEN LIVING WITH HIV – part 2

- If women living with HIV *don't* start treatment right away, then there are valid reasons for why we do that, including keeping safe.
- If women go home with medication or if they are pushed into 'disclosure', when they don't feel safe at home, then they will fear what is going to happen both to themselves and to their children.
- So *not* taking medication and *not* telling anyone is often the safer and rational decision.
- Policy makers and researchers need to understand and address this reality as a matter of urgency.

4) Questioning the current formal research paradigm: is it fit for purpose?



‘EXPERTISE BY EXPERIENCE’ OR ‘ANECDOTE’?

- Many years of activism around the world have produced a plethora of reports and case studies.
- In Namibia, the Namibia Women’s Health Network even took the Namibia Ministry of Health to court to challenge its practice of forced or coerced sterilisation of women living with HIV after childbirth.
- They were given the paper to sign while in labour, at the same time as they signed their consent to a caesarean section.
- The Namibia Women’s Health Network eventually won.
- But none of these reports made it into peer-review journal articles.
- So they are all described as “**anecdotal**” by formal researchers and policy makers.



“anecdotal”

Questioning the conventional hierarchy of evidence – part 1

- This is because there is a hierarchy of what is considered as acceptable ‘evidence’, with systematic reviews of Randomised Control Trials (RCTs), and RCTs themselves at the top, and stories, reports and other ‘grey literature’ at the bottom.
- There are strict rules around what is admissible as ‘evidence’ for publication in peer review journals and to shape WHO Global Policy Guidelines. This is good to make sure that medication is safe, but there is an increasing realisation that such stringent rules are not enough when conducting research into psycho-social community-based programmes. This is partly because formal quantitative research can be too expensive for many NGOs to conduct, especially if eg blood tests are involved. It is also because such research normally defines success in terms of one or two primary outcomes – eg ‘does X produce result Y?’.
- However, many years of experience show us that people’s lives are messy and complex, with many different factors at play. There are no simple answers to complex situations. Our lives are not siloed into health, education, social care, finance, housing, food, water etc. and access to and availability of all these factors and more can influence our ability to stay HIV-free and safe.
- However things are changing.....

Questioning the conventional hierarchy of evidence – part 2

Figure 4: Conventional hierarchy of evidence

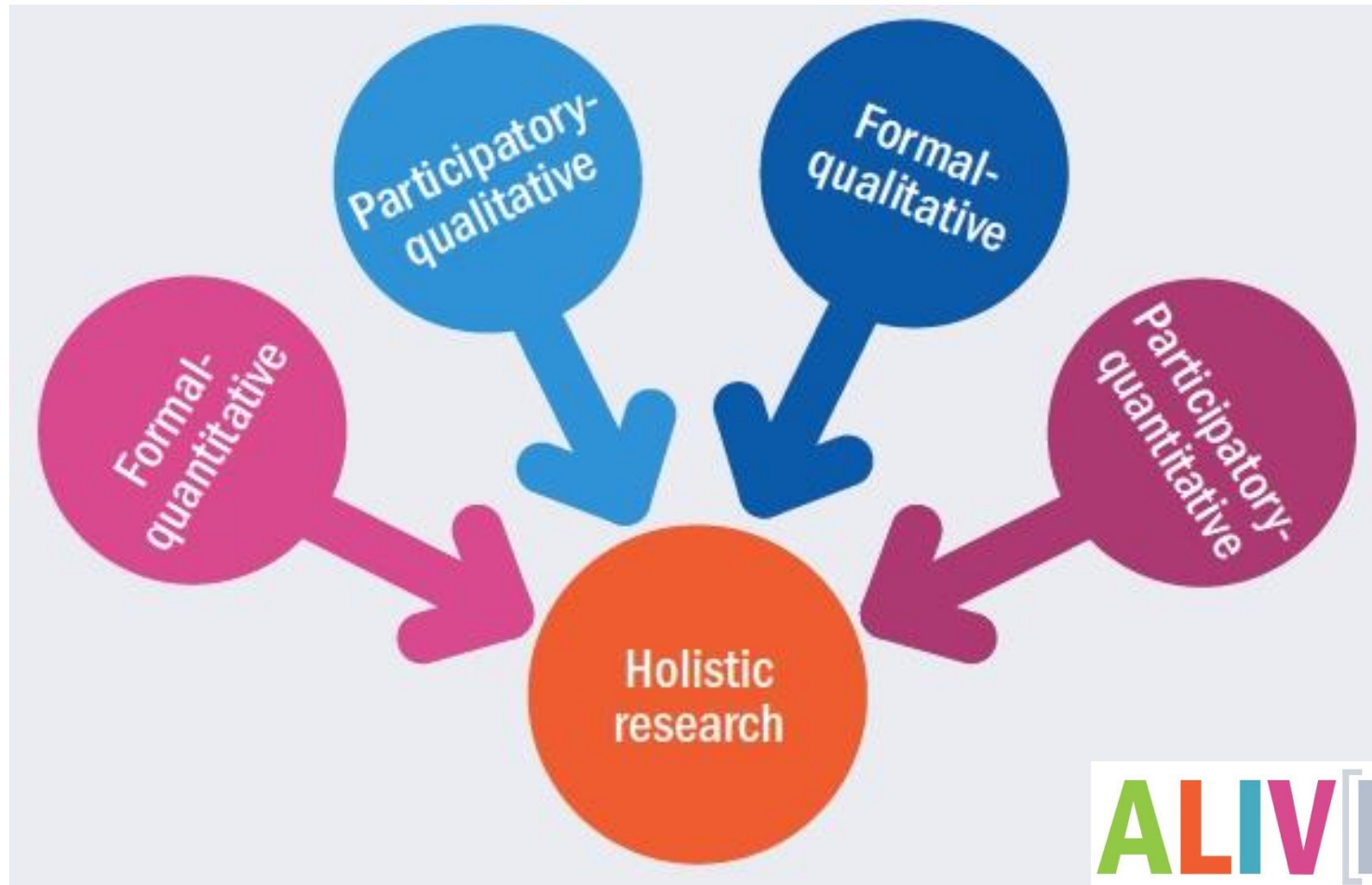


So what we are really missing out on here is the wealth of insights, knowledge and experience of what works – and what *doesn't* work - at grassroots community level. After the huge tsunami in 2005, an inquiry recommended that states should draw much more in future on regular monitoring of *local* knowledge, as an early warning system, rather than just depending on scientific data. People often know from watching animals, or a change in air pressure, that something big like a tsunami or eclipse is about to happen. This local knowledge is just that – local, contextualised – and needs to be recognised, valued and appreciated for its vast wealth of insight.

Moreover, if you have local people monitoring and evaluating programmes on their own terms, especially if they have been involved in the programme creation, there is an immediate natural curiosity in tracking their progress. This leads to a sense of pride, ownership and sustainability of the programme, long after the NGO or researchers have packed up and moved on.

So there is a win win here in expanding and strengthening our evidence base to include not only *formal* quantitative and qualitative research, but also *participatory* quantitative and qualitative research processes also, as parallel systems across the life-course of a project - and beyond.

5) Strengthening and expanding the evidence base: the UNAIDS et al ALIV[H]E comprehensive research approach



ALIV[H]E

Action Linking Initiatives on Violence Against Women and HIV Everywhere

framework

Human rights

ALIV[H]E

Action Linking Initiatives on Violence Against Women and HIV Everywhere

framework



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UNFPA
UNODC
ILO
UNESCO
WHO
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1. Human rights This relates to the core principle 'driven by a human rights approach' surrounding the 16 ideas wheel. We see it as holding the whole framework in place

2. Sexual and reproductive health and rights This relates to the core principle 'at minimum do no harm' surrounding the 16 ideas wheel

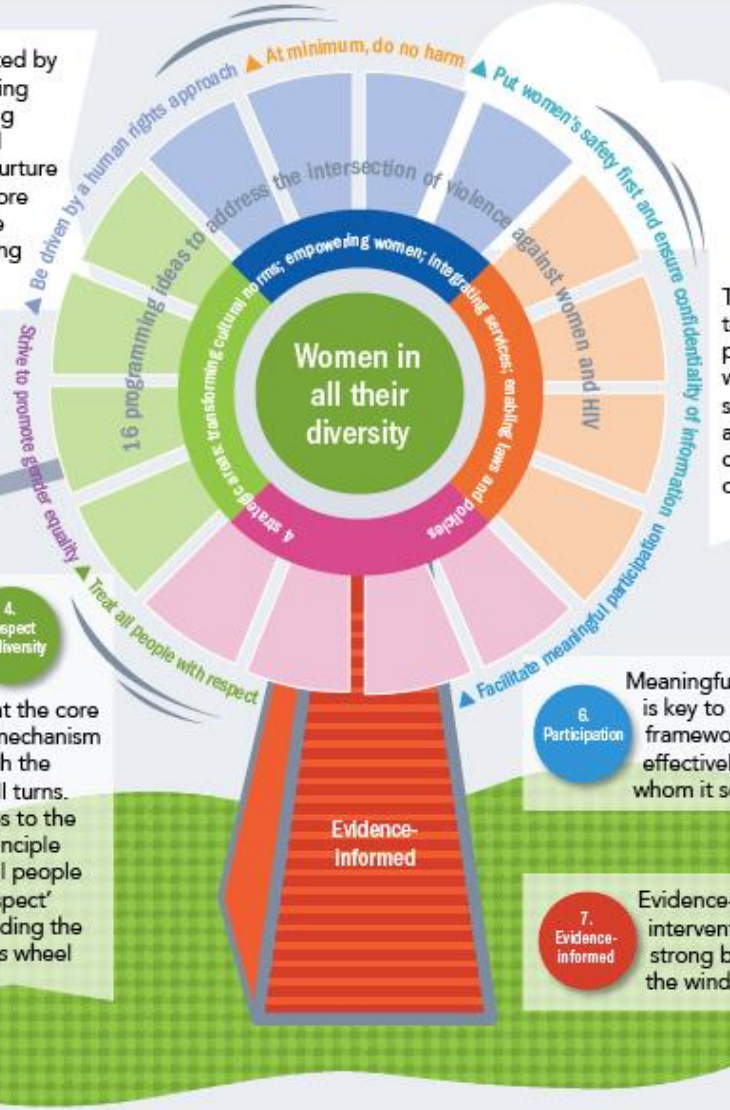
3. Gender equity and equality This is represented by the vane, catching the wind, turning the windmill and drawing water to nurture the land. It relates to the core principle 'strive to promote gender equality' surrounding the 16 ideas wheel

5. Safety This relates to the core principle 'put women's safety first and ensure confidentiality of information'

4. Respect for diversity This is at the core of the mechanism by which the windmill turns. It relates to the core principle 'treat all people with respect' surrounding the 16 ideas wheel

6. Participation Meaningful participation is key to making this framework work effectively for those whom it seeks to support

7. Evidence-informed Evidence-informed interventions form the strong base upon which the windmill stands



Principles of Participation

A. INTRINSIC RIGHTS

Universal Declaration of Human Rights 1948: Article 27

1) *Everyone has the right freely to participate in the cultural life of the community, to enjoy the arts and to share in scientific advancement and its benefits.*

This gives women in communities the right to participate in research - which is scientific advancement

2) *Everyone has the right to the protection of the moral and material interests resulting from any scientific, literary or artistic production of which he is the author.*

This gives women in communities the right to meaningful involvement & ownership of the information that we provide

Principles of Women's Participation – some key documents

1948 Universal Declaration of Human Rights, Article 27

1976 Our Bodies Ourselves - Boston Women's Health Collective

1979 CEDAW

1983 Denver Principles – GIPA

1993 *Nothing about us without us.....* S. Africa disability rights

2001/16 WHO Ethical Recommendations on research on VAW

2004 ICW - MIWA – participation tree

2004 ICW Gdlnes on Ethcl Prtrpry Rsrch w women with HIV

2006 CRPD Disability Rights

2013 Sex Worker Implementation Tool (SWIT)

2015 INPUD / ICW Position Statement

2015 TRANSIT UNDP doc on trans rights

2016 ILGA World Survey 11th Edition

2017 WHO Gdlnes on SRH&R of women living with HIV



Participation

Principles of Participation

B. INSTRUMENTAL BENEFITS

- If people want to have programmes which are acceptable, accessible, affordable, sustainable, *and accountable to those most affected* then the sooner they *involve* those most affected by the issue in the programme design, development, implementation, monitoring and evaluation, the better.

Gradual realisation of the importance of this.

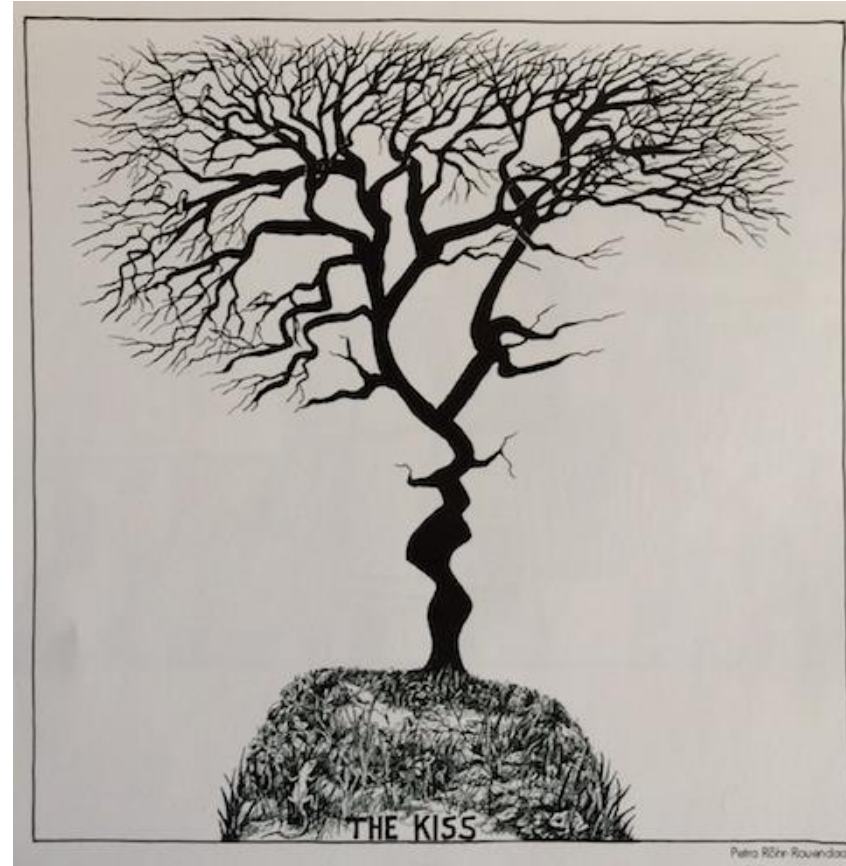
- **Eg the WAVE Study:** 2011-3, Johns Hopkins Bloomberg School of Public Health
 - 5-city international project on young people 15-19 years
 - quantitative questionnaire developed first
 - conducted the qualitative work (photo-voice, community mapping and IDIs.)
 - Qualitative study made them rewrite the quantitative questionnaire
- **Eg Julia Kim: (Raab and Stuppert):** "Participation also tended to deepen the evaluators' understanding of the intervention and its participants."
- Eg - **Chicago presentation R4P** 2016 - Most of studies on VAW are *in* Africa but only 15% of researchers *are* African.

- So it is time to turn this pyramid on its head and see how we can best harness in a systematic way the wealth of information available in its widest row.
- This is not ‘corrupting’ the data – it is substantively enhancing it. It is recognising our need to depend not just on ‘*evidence-based*’ data (which is what formal research is often called), but also ‘*evidence-informed*’ data – which is often the how and why.
- This is what we have done in the ALIV[H]E Framework.

Questioning the hierarchy of evidence



Different viewpoints..... what can *you* see?

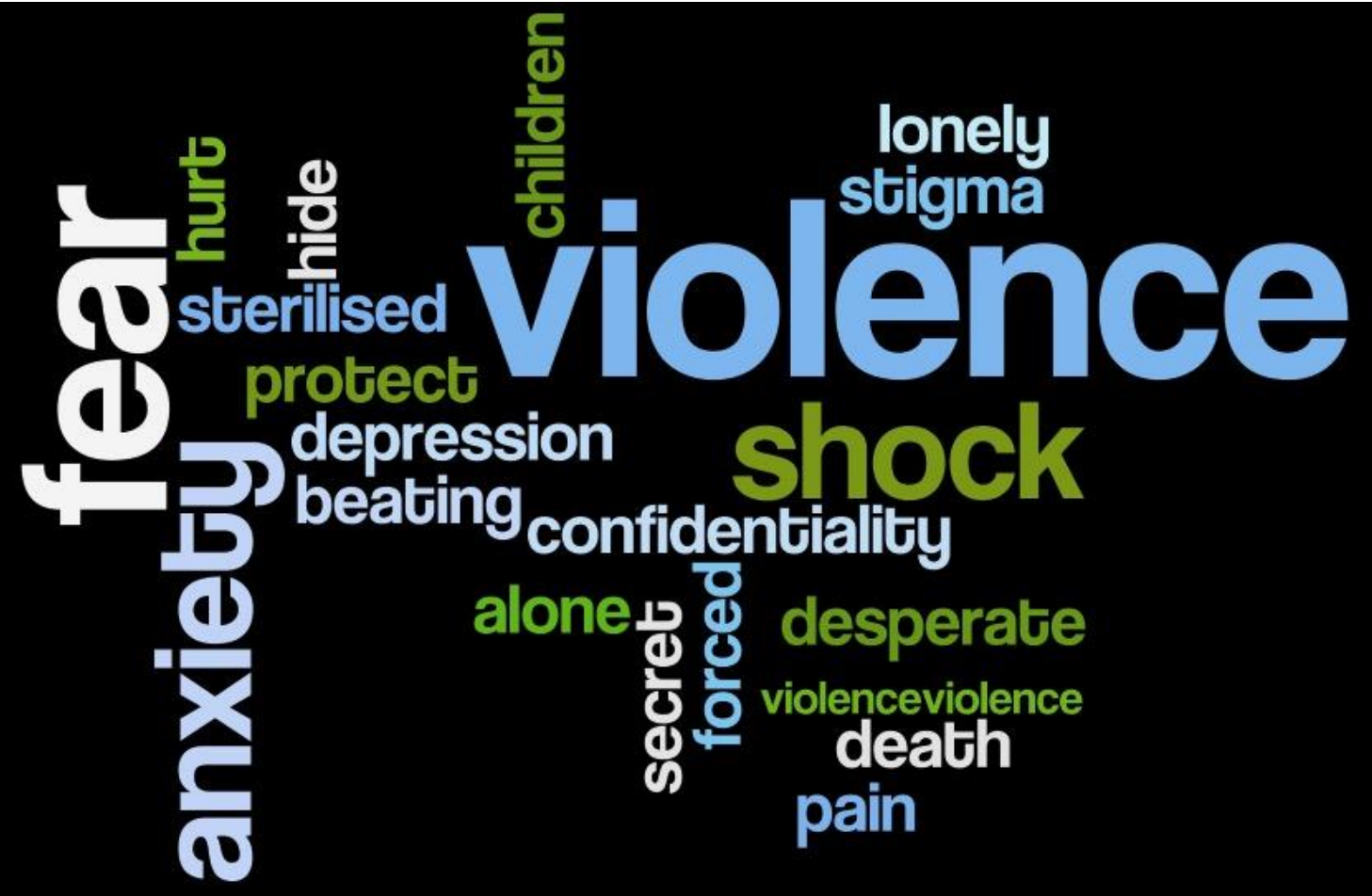


Perspective of policy-makers & healthcare providers

A word cloud of terms related to HIV/AIDS treatment and management. The words are arranged in a non-linear fashion, with varying sizes and orientations. The most prominent words are 'disclose', 'infect', and 'treatment'. Other significant words include 'PMTCT', 'defaulter', 'drop-out', 'default', 'VL', 'routine', 'lost-to-follow-up', 'HIV', 'CD4', 'sero-discordant', 'AIDS', and 'stop'.

PMTCT defaulter
disclose stop
lost-to-follow-up drop-out
HIV VL
default routine **infect** CD4 sero-discordant AIDS
treatment

Perspective of women living with HIV



As we learnt from earlier slides, from the perspective of a newly diagnosed woman, she may just be wanting to keep herself and her older children safe.

And she may be experiencing shock at having just received a potentially fatal diagnosis.

What she needs first and foremost is care, respect, dignity and support.

So how can we access women's experiences and perspectives? In the next slide is an example from a grassroots programme in Kenya in May 2017, which trains women living with HIV as 'mentor mothers' to support other women living with HIV on their pregnancy journey.

This participatory visioning exercise clearly showed that women primarily wanted hygiene, hospitality, information, access to medication and care, rather than to know what their CD4 count or viral load might be.

If we put women's own priorities first, then they will feel valued and respected and the rest is more likely to follow.

The ALIV[H]E Framework is about *seeing* things differently - through women's eyes.



“My partner was very angry with the diagnosis and was blaming me for it... One day after an argument I was beaten black and blue.”

4M Creative Writing

“The training was fantastic. I am glad I participated. I have come to understand that there is help out there. I don't have to suffer alone. I just have to know where to go and what to do.”

4M Mentor Mother, Leicester

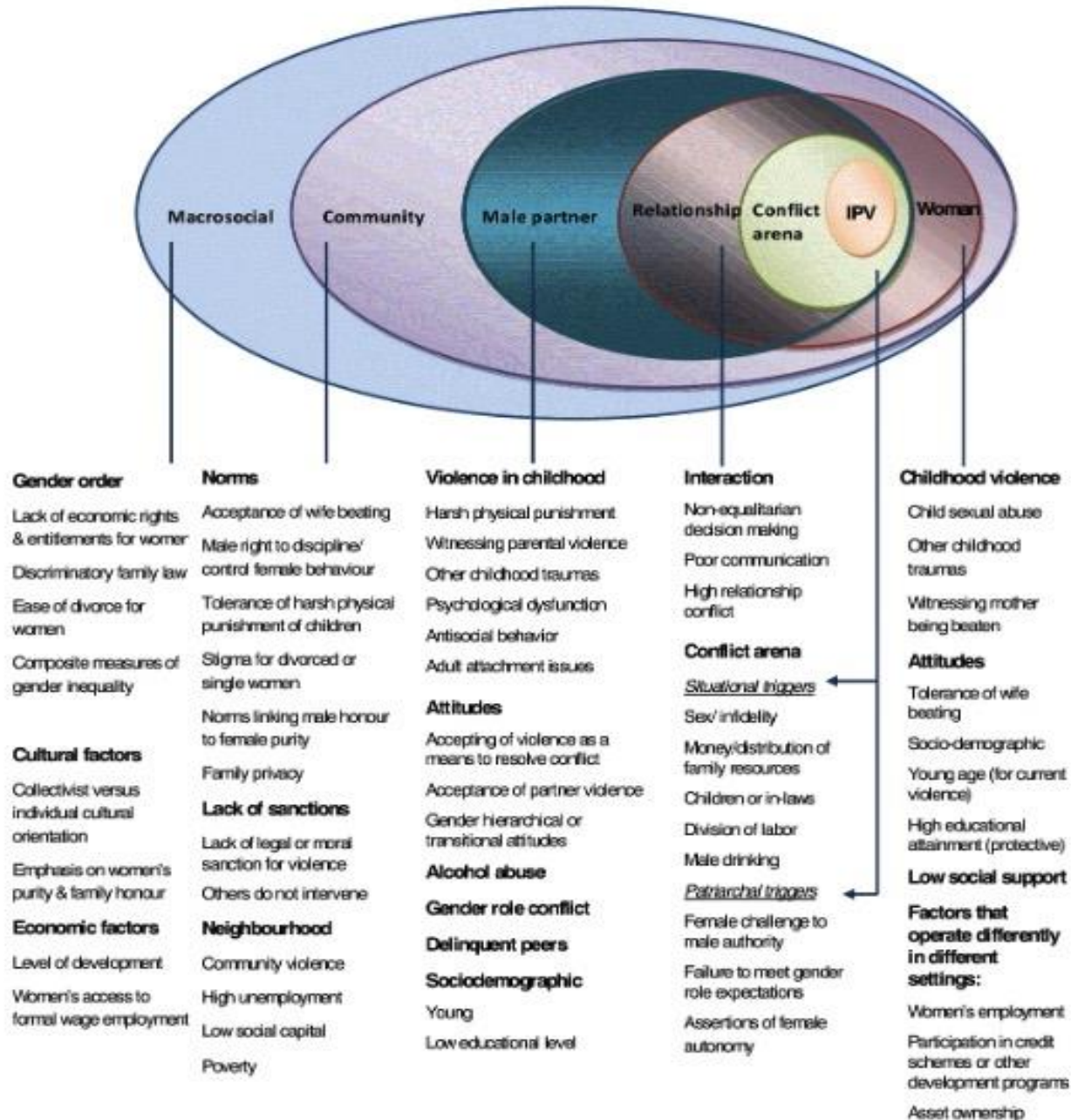


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TRANSFORMING THE WAY WE THINK ABOUT...

Many are familiar with the socio-ecological model, adapted by Heise and others to look at partner violence conceptually.

This highlights some of the many different factors mentioned earlier which contribute to partner violence and other forms of violence against women.

Figure 1.2 Revised Conceptual Framework for Partner Violence



Heise, L. (2011)
What works to prevent partner violence: an evidence overview. STRIVE Research Consortium

However this model, while useful, only works on one axis – from the individual woman across wider society.

As we have seen, this can still be too simplistic.

Society



Individual



So instead we have used the Change Matrix model, developed by Gender at Work[®] and adapted by the Global Fund for Women and others.

This takes these two points, turns them onto a vertical axis and adds a new horizontal axis, representing formal and informal ends of the spectrum in our societies globally.

Individual



Informal

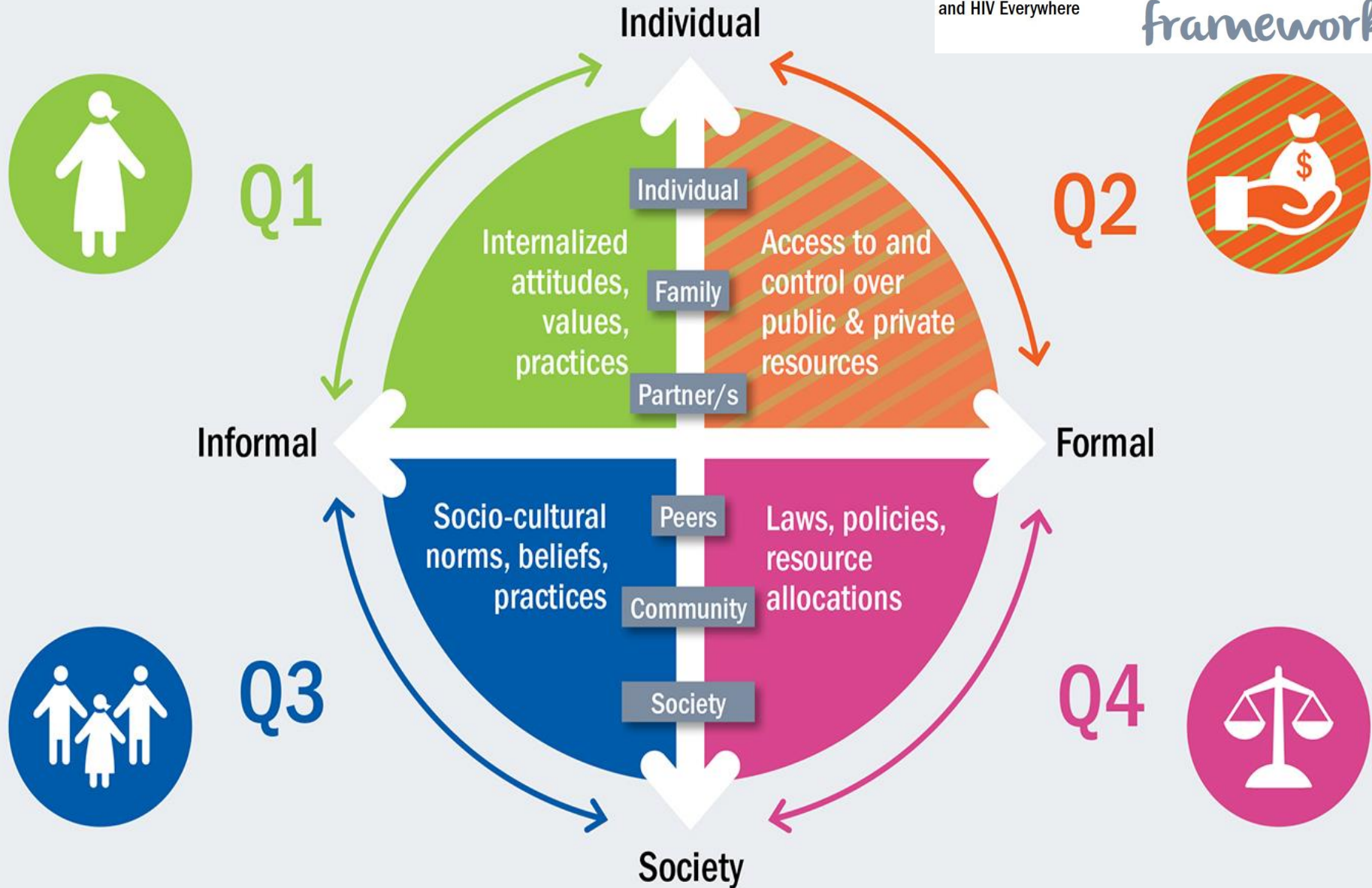


Formal



Society

Figure 5: The change matrix⁶⁵



You can still see the different stages of the socio-ecologic model, now running from the individual at the top to society at the bottom. This is intersected by the horizontal axis which considers more informal spaces on the left and more formal spaces on the right.

During our research for the development of this framework, it became clear that many of the indicators that are used to chart HIV and Violence Against Women at national and global levels relate much more to the formal quadrants on the right of the matrix: nos. 2 and 4; and much less to the informal quadrants, nos. 1 and 3.

Our analysis showed that the quadrant which has the fewest indicators, no. 1, is the one most relevant to a woman's own psycho-social beliefs, feelings, thoughts and actions.

We still have a lot to learn and understand about women's own beliefs, feelings, thoughts and actions, from their own perspectives; and how best they can be supported to overcome the challenges they face with regard to violence against women and HIV. And we need to ask them to create indicators which work for them.

This is why *analysing* things differently – using participatory approaches to this work – is so important.

This is how the ALIV[H]E Framework can help us.

A new windmill of change has been produced for the ALIV[H]E Framework. The circle of the windmill is the WHO *16 Ideas Wheel*, which describes programmes that we know to be effective.

Around the windmill, we see all the elements raised earlier – the human rights, the safety, the meaningful participation, everything needing to be evidence-*informed*, rather than only evidence-*based*, with a strong wind blowing in of gender equity and equality.

It is with all this support around it, that this windmill of change can work, drawing out water out from the deep as it turns, to irrigate all the land around it, enabling life to flourish.

Women in all their diversity are at the fulcrum of this windmill.

Human rights

ALIV[H]E

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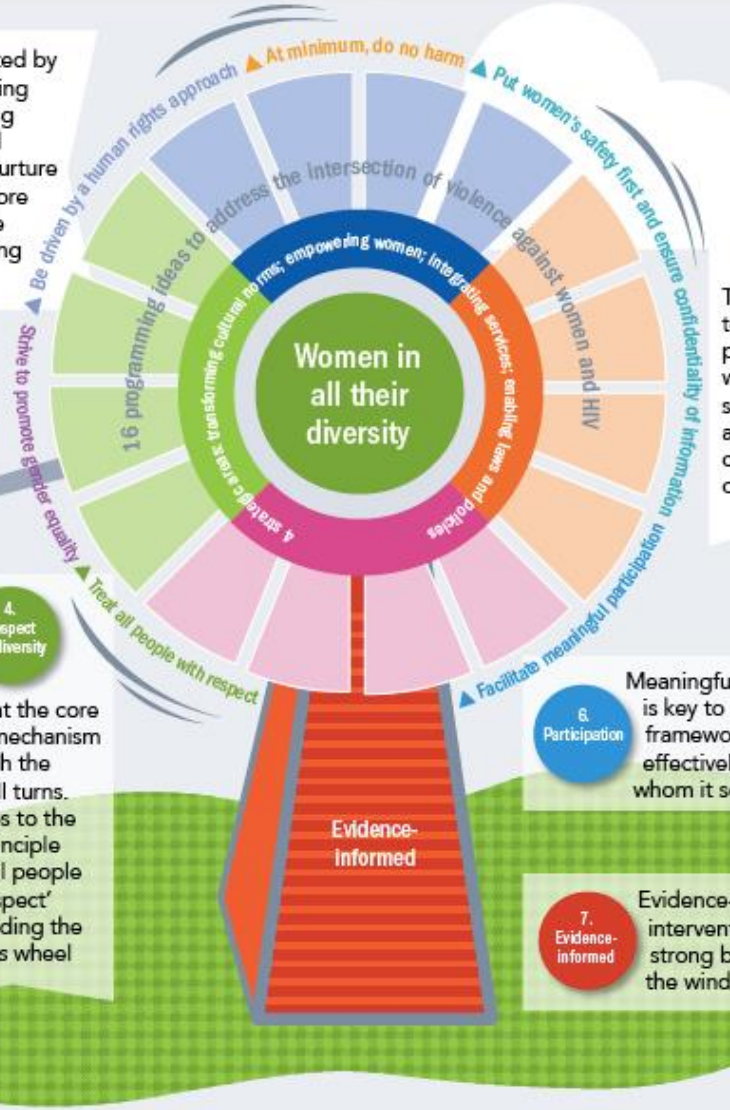
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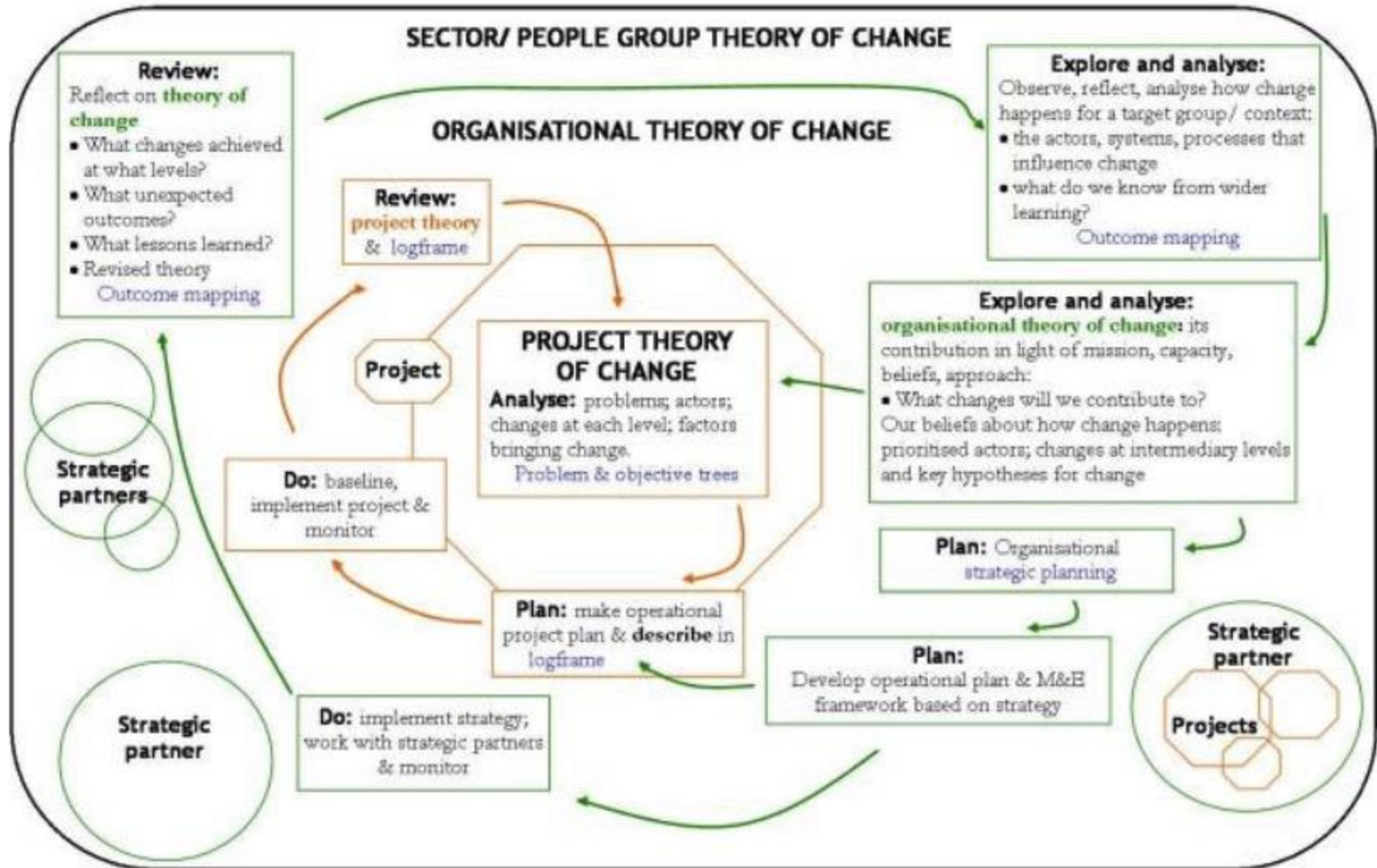
What is the ALIV[H]E Theory of Change?

There are many different formats for a theory of change. We wanted one with which community members could identify also, so they could be involved from the outset in designing, running, monitoring and evaluating a programme which works specifically for *them*.

We found this one from a DfID Report in 2012.

MACRO THEORY OF CHANGE

Explore: broad social change theories



Source: Comic Relief - Theory of Change Review, C. James (20110)

Demonstrating the power of a good visual, Comic Relief's Learning and Evaluation Continuum illustrates how theory of change thinking can add value throughout the organizational strategic planning, project cycle

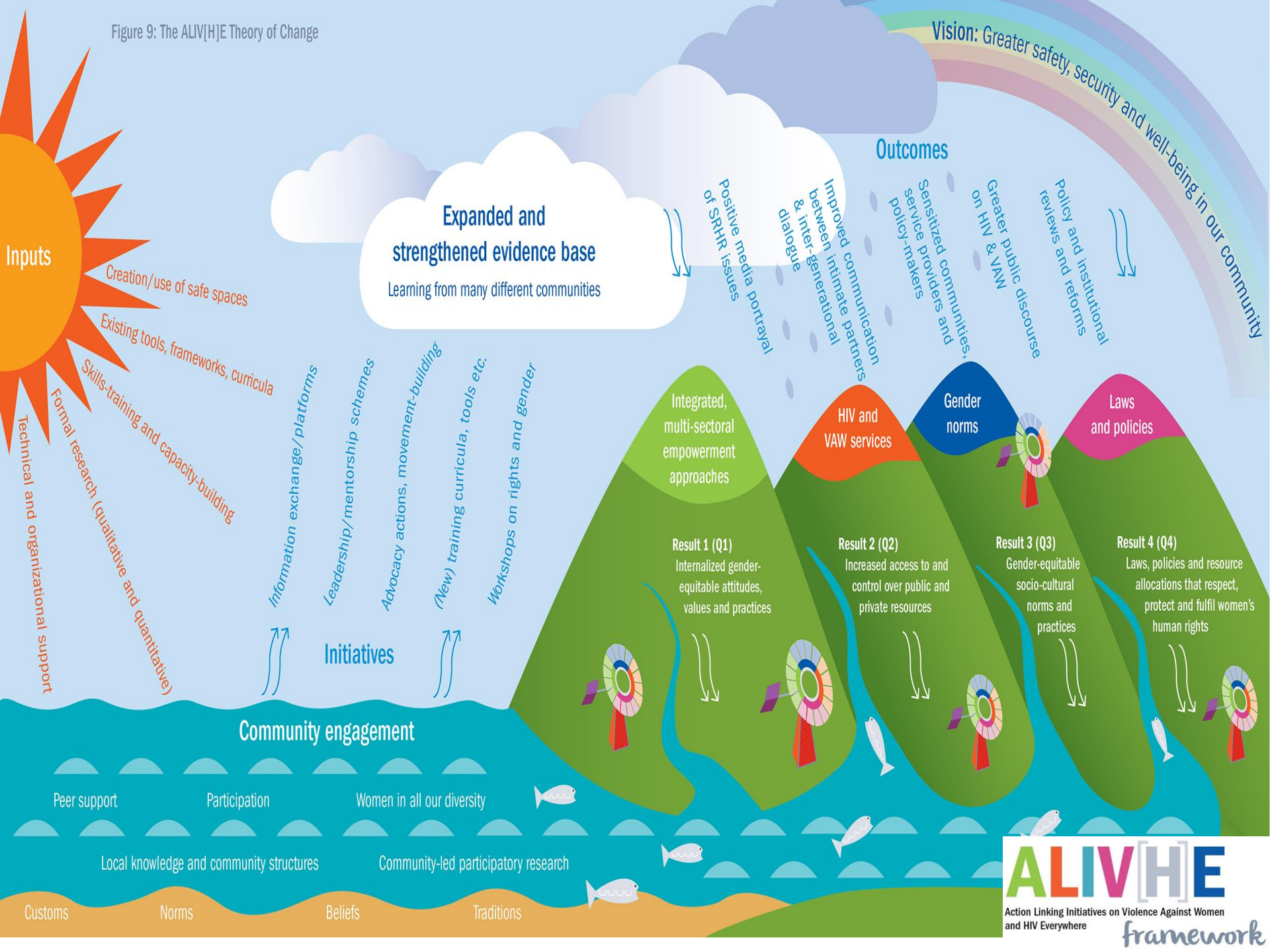
This was a helpful variation on the linear flowchart approach which characterizes many theories of change. Yet we wanted one with more movement in it, more flow, more features, more complexity and adaptability, whilst also being understandable to anyone.

We chose a landscape theory of change, because everyone has their own landscape around them, so this can be adapted to any context. It has many different elements and the changes are also represented by and connect to a weather system which links them all. Nothing is siloed, everything is connected. A weather system is again something common to us all, yet different in every place.

There are even little fish swimming upstream, against the normal flow, to represent activism, trying to change things in a different way.

So this is how we can *do* things differently – the ALIV[H]E Framework enables us to include key community members in the whole programme development process from the outset.

Figure 9: The ALIV[H]E Theory of Change



In conclusion, the ALIV[H]E Framework enables us to see, analyse and do things differently. It has been designed to create, monitor and evaluate community-based programmes which are based on women's own lived experiences, and which enable those most affected to be centrally involved in this throughout.

We urgently need research and policy to align themselves with an evidence base which is systematically informed by women's lived realities.

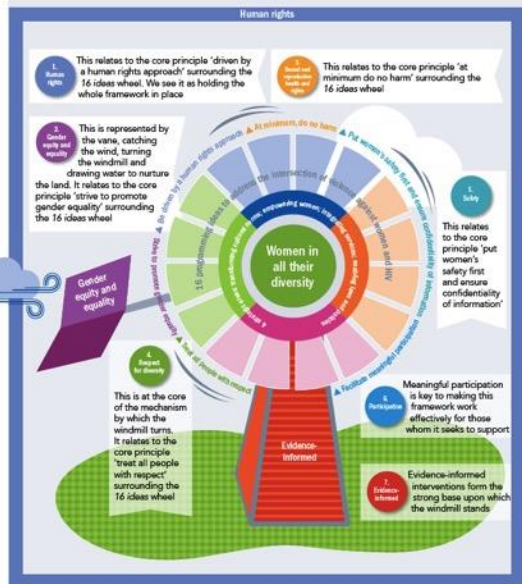
And we need programmes which are meaningful, equitable, just and effective for women and adolescent girls, in the context of violence against women and HIV and the imperative to have the SRH&R of all women, in all their diversity, upheld.

We trust that this process will enable us all to expand and strengthen the evidence base around these programmes, through this holistic approach to comprehensive, collaborative research.

The ALIV[H]E Framework document is coming out shortly and will be available through this website: <http://tinyurl.com/ALIVHEUNAIDS> as well as a dedicated UNAIDS site.

There are also other related materials available on this website.

More will continue to be added from NGOs in different countries that have piloted this approach in their own work.



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ALIVHE
Action Linking Initiatives on Violence Against Women and HIV Everywhere
framework

