

The Adherence Networking Group

The Adherence Networking Group (ANG) was formed in 2004 to explore issues around adherence to antiretrovirals (ARVs). A group of professionals from various sectors in Gauteng who work in the fields of ARV treatment, adherence counselling and support come together once a month to share ideas, swap resources and promote increased understanding and skill around assisting people on ARVs to adhere.

The success of ARVs is dependent partly on the ability of the individual on treatment to stick to the required regimen. This means taking the medication according to the prescribed instructions i.e. the recommended dose, at the recommended time and in the recommended way. Studies have shown that in order for one to be adherent, one should take at least 19 out of 20 doses. This means that an adherence rate of more than 95% must be sustained in order for there to be virological control (i.e. control of HIV). The ANG believes strongly that while adherence is possible, those on treatment need preparation and support for what is a lifelong journey. It also recognises that adherence can fluctuate over time within an individual's treatment history and that achieving adherence in the developing world, while not impossible, needs creative and fresh ideas.

One of the first objectives of the ANG when it started was to pool its ideas and develop a tool to assist anyone with an interest in adherence support, but especially trainers of adherence counsellors, to access the experience and wisdom of the group. This tool became known as the Adherence Resource Pack (ARP). A version of the pack started out in 2003 when it became clear that the South African government was committed to providing ARVs in the public health sector in 2004. Initially, a counselling course on adherence for lay counsellors was developed by Kerry Saloner for the CSA at UP. Later it became clear that others involved in treatment needed information on adherence counselling and support. The original course material was expanded into the ARP, a comprehensive resource for anyone who works in adherence support and training: lay counsellors, nurses, doctors, psychologists, social workers pharmacists, dieticians and treatment assistants. The settings where optimum usage was envisaged are roll-out sites, clinics and hospitals, both rural and urban. However, the pack would be just as useful to a GP in private practice or someone wanting to find out more about adherence in general.

The pack can be utilised as guidance in any ARV related strategy. It has sections on:

1. General background information and research.
2. ARV adherence counselling for those who have HIV counselling skills in place.
3. A trainer's guide to adherence counselling and support with relevant exercises and guidelines.
4. Information sheets for both counsellors and clients – in the form of checklists and summaries – which enable them to refer to information received in the counselling or support session.
5. Sample training curricula and instructions on how to use them in different contexts.
6. Resources listing ARV service providers and organisations.

The ARP is a constantly evolving product, keeping abreast of all of the emerging issues in ARV provision. Currently a very experienced task team is working on developing materials aimed at promoting adherence in children, which should be available early in 2006. Headed by Ray Lazarus, a psychologist based at the Perinatal HIV Research Unit (PHRU) at Chris Hani Baragwanath Hospital, this team, in collaboration with key people at Harriet Shezi Children's Clinic, Tara-Alex Children's Clinic, Ekupholeni and the AIDS Law Project, will be exploring issues such as: child development and antiretroviral therapy; psychosocial issues affecting the family; psychosocial support in resource-limited settings; treatment literacy; disclosure in the case of children; legal issues; supporting effective parenting; grief and loss in children; background medical information required for effective adherence counselling in relation to children and adaptations to adherence counselling for the various childhood stages.

The ANG recently held a very successful Adherence Symposium (see link to the presentations at this symposium) and other proposed projects include a train the trainer workshop to skill up trainers who wish to run adherence counselling courses; obtaining accreditation for the adherence counselling course, developing a video on adherence counselling and developing a module on adolescents and adherence, while continuing to promote the ARP. It is worth noting that the ANG does not receive any formal funding for its activities and all members are volunteers. Apparently collaborations of this nature are unusual in the NGO world and two ANG members were recently interviewed by a researcher exploring such collaborations. Special mention should be made of Lauren Jankelowitz of Community AIDS Response (CARE) for providing a venue for all meetings, and the PHRU and the CSA for funding of the ARP.

To get a hard copy of the Adherence Resource Pack please contact Helen Struthers of the PHRU at 011 989-9700 or click on the link for a PDF version. For any further information regarding the Adherence Networking Group please contact Saranne Meyersfeld on 082 3770737 or Pierre Brouard on 012 420 4391.

The ANG core members are Pierre Brouard of the CSA, Lauren Jankelowitz of CARE, Helen Struthers of PHRU, Robin Hamilton of Aurum Health, Saranne Meyersfeld of AIDSTEC and Thulani Grenville-Grey of the Reproductive Health Research Unit (RHRU). Francois Venter of RHRU is the main medical consultant of the ANG and new members are Bridget Hingst of Right to Care, Karen James of HIVSA, Vuyo Kuboni of the CSA, Ray Lazarus of PHRU, Langi Malamba of Soul City, Rebecca Pursell of Wits University and Tumi Tshabalala of PHRU.