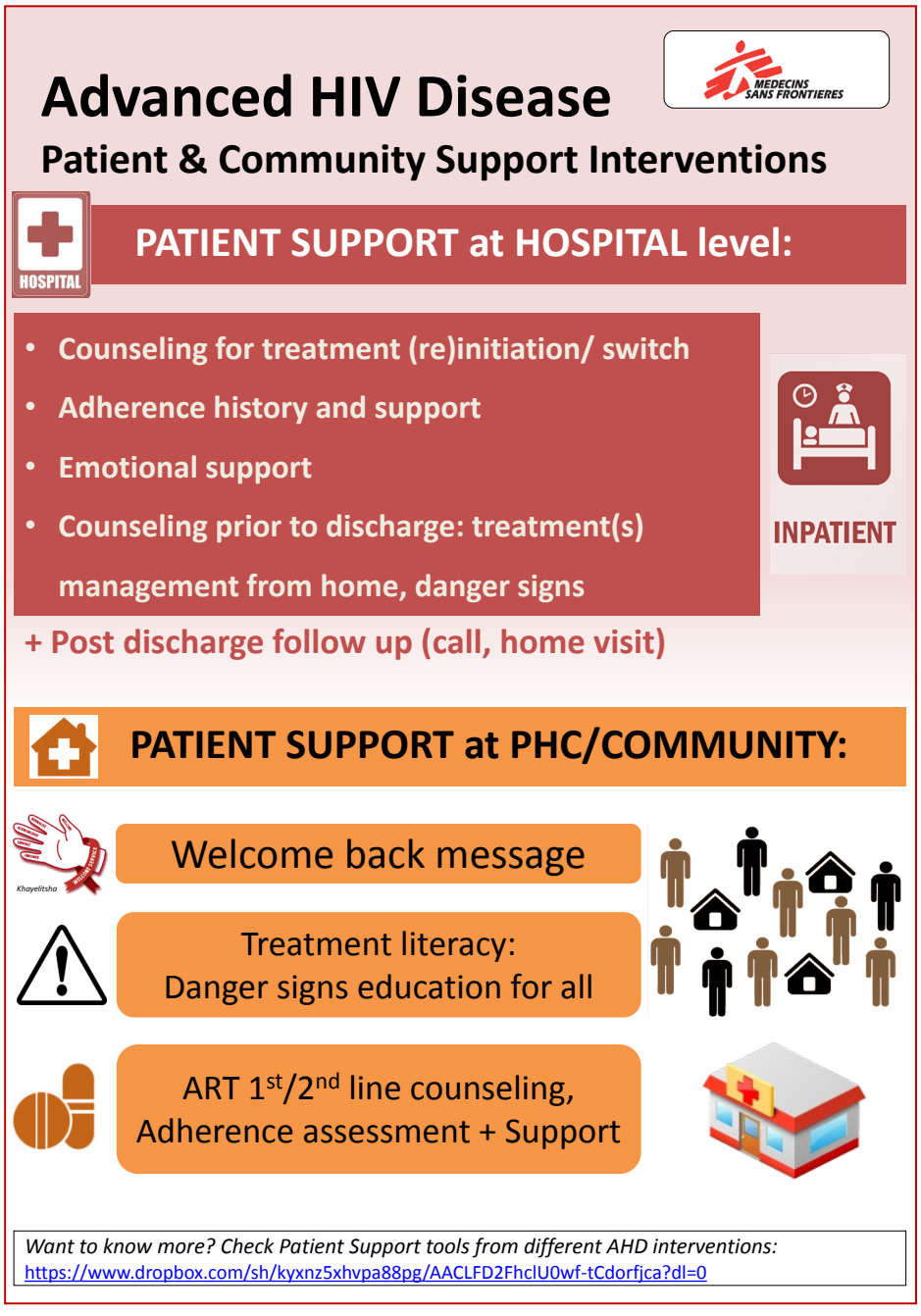
Patient & Community Support for Advanced HIV Disease

Patient & Community Support (PCS) interventions specific to Advanced HIV Disease (AHD) aim at supporting patients to **cope with the complications of HIV** at this advanced stage and to **deal with ART and all necessary treatment(s) requirements** - beyond the purely medical aspects of care. AHD PCS covers support activities ranging from health promotion/raising AHD awareness in community to counseling and mental health support at Primary Health Care (PCH) and inpatient/hospital level.

The figure below summarizes the core PCS activities at PCH, Community and Referral/Inpatient level. The detailed description and examples of each PCS activity are presented separately in the following two sections: PHC and Referral level



1. Patient & Community Support for AHD at PHC level

PCS for AHD patients:

AHD Patient Support at Primary Health Care level entails educational and counseling activities, treatment adherence support tailored to patient's needs and patient tracing if/when is needed. More precisely, PCS for AHD includes:

- Standard ART counseling (for 1st line or switch to 2nd line treatment) **including explanations on AHD and patient's condition** (see Annex 1: example from Khayelitsha on how to explain AHD to patients);
- **Danger signs education,** ideally supported by a visual aid tool, (see annex 2: example of danger signs leaflet form Nsanje, Malawi);
- **Assessment of adherence** challenges, reasons for treatment interruptions in the past (for ART experienced patients) or assessment of reasons for not coming earlier to Health Facility (HF) to seek for medical care (for ART non-experienced patients), (see Annex3: example from KZN, South Africa on how to assess adherence history of patients);
- **Adherence counseling support** with a new personalized adherence plan so patient can manage the best way possible their adherence to ART and other OI treatments/ prophylaxis, (refer to MSF PSEC guidelines, standard ART/TB adherence plan)
- **Close follow up** until patients are stable **and fast patient tracing** (through phone calls and/or home visits by community health workers) when patients are missing appointments, (refer to each project's tracing system without delays). If possible, and without implying any criticism, a specific counseling session can be provided for patients returning to HF after they have missed their appointments (refer to annex 4: example from Nsanje, Malawi about counseling patients who missed appointments)

Awareness on AHD and welcoming approach for all HIV patients:

PCS for AHD also includes **community awareness and treatment literacy** targeting all HIV patients (regardless the disease progress). More precisely:

- All HIV patients should be well aware of danger signs and when to come back to HF earlier than their appointment date. **Danger signs education** (annex 2) should be thus included at all levels, in any occasion a patient education or counseling session takes place with an HIV patient:
    - During ART initiation counseling sessions,
    - Adherence Follow up counseling,
    - Enhanced Adherence Counseling session,
    - Counseling for switching treatment,
    - Group support sessions,
    - During health talks in the waiting areas in HF and in community when possible

- A **"welcome" message** should be also incorporated in individual and group sessions in HF and along with health promotion activities at community level. This is to emphasize the importance for HIV patients to returning to ART care in case they have been disengaged temporary or for long time.

Overall, the quality of the **relationship between the health care providers and the patients** is highly important and can determine the outcomes of care. This should be thus based on a welcoming, trustful, non-judgmental approach.

- Sensitization workshops, **trainings to Health Care staff** about attitudes and supportive communication are also part of PCS activities aiming at reinforcing a welcome approach of HCP towards patients

➔ **A summary of PCS interventions at PHC level from Beira Mozambique can be found in annex 5**

2. Patient Support for AHD at Referral/Inpatient level

PCS for hospitalized AHD patients:

Patient Support at hospital level is an important component of the care provided to AHD patients. It consists of all educational, counseling and emotional support activities targeting the patients (and their family/caregivers when possible). Patient support should be provided always with respect to patients' health condition, its severity and possibility to communicate effectively with health care providers.
More precisely, Patient Support at hospital includes:

- Fast track ART (re)initiation counseling or switch treatment line counseling, **including explanations on AHD and patient's condition** (see Annex 1, example from Khayelitsha, S. Africa on how to explain AHD to patients);
- **Assessment of adherence history** or of reasons for treatment interruption in the past or reasons for not coming earlier to seek medical care, (see Annex 3 or annex 6: example from Nsanje, Malawi) ;
- **Adherence counseling support** with a new personalized adherence plan so patient can manage the best way possible their adherence to ART and other OI treatments/ prophylaxis, (refer to MSF PSEC guidelines, standard ART/TB adherence plan)
- **Danger signs education,** ideally supported by a visual aid tool, (see annex 2: example of danger signs leaflet form Nsanje, Malawi);
- **Counseling prior to discharge**, to review adherence plan, explain counter-referral to PHC, post-discharge follow up and treatment management from home, (see annex 7, example from Nsanje, Malawi: pre-discharge counseling session and checklist for counselor)
- When possible, Family planning needs to be included in the follow up counseling; also index testing should be proposed along with group education sessions to family members/caregivers

Post-discharge Follow Up:

- Post-discharge follow up is necessary to ensure the AHD patient remains in care and is closely followed up at PHC until his health condition is stable
- An example from Nsanje, Malawi can be found in annex 8, describing post-discharge phone calls until Month 3 post-discharge
- When phone calls are not an option a system of patient tracing can be put in place through for example home visits by community health workers