



UNHCR's Principles and Guidance for Referral Health Care for Refugees and Other Persons of Concern

Public Health and HIV Section Division for Programme Support and Management December 2009



#### © UNHCR, 2008. All rights reserved.

Reproduction and dissemination for educational or other non-commercial purposes is authorised without any prior written permission from the copyright holders provided the source is fully acknowledged. Reproduction for resale or other commercial purposes, or translation for any purpose, is prohibited without the written permission of the copyright holders. Applications for such permission should be addressed to the Public Health and HIV Section of the Office of the United Nations High Commissioner for Refugees at hqphn@unhcr.org

All reasonable precautions have been taken by the United Nations High Commissioner for Refugees to verify the information contained in this publication. However, the published material is being distributed without warranty of any kind, either express or implied. The responsibility for the interpretation and use of the material lies with the reader. In no event shall the United Nations High Commissioner for Refugees be liable for damages arising from its use.

Copies of this document can be obtained from: UNHCR – Public Health and HIV Section CP 2500 1202 Geneva, Switzerland hqphn@unhcr.org and from the website: www.unhcr.org/health

# UNHCR's Principles and Guidance for Referral Health Care for Refugees and Other Persons of Concern

**Public Health and HIV Section Division for Programme Support and Management** December 2009

# Table of Contents

1.	List of	Acronyms	2
2.	Objec	tive	4
3.	Defini	tions	4
	3.1	Primary health care	4
	3.2	Referral health care	4
	3.3	Persons of concern (PoCs) to UNHCR	4
4.	Introd	luction	5
5.	Challe	nges	5
6.	Ten Gi	uiding Principles	7
	6.1	Clear target group definition(s)	7
	6.2	Primary health care is first level of care	7
	6.3	Avoid use of parallel systems and build on existing structures	7
	6.4	Equity of care and access between PoCs and host populations	7
	6.5	Referral is a medical decision	9
	6.6	Referral decisions are mainly based on prognosis and cost	9
	6.7	Secure transparency of process through consultation, clear communicatio and widespread dissemination	
	6.8	Appropriate contractual agreement with service providers	12
	6.9	Coordinate with and support prevention programmes for main diseases referred	13
	6.10	Explore all possibilities for referral	13
7.	Monit	oring and Evaluation	14
	7.1	Initial assessment	14
	7.2	Monitoring framework	14
	7.3	Referral care indicators:	14
	7.4	Cost of referrals	15
	7.5	Evaluation	15
8.	Conclu	usions	16
9.	Annex	x: Example of terms of reference for referral care committee	18
	Annex	: Glossary and standard definitions	20

# 1. List of Acronyms

HIV	Human Immunodeficiency Virus
IDP	Internally Displaced Person
IP	Implementing Partner
PHC	Primary Health Care
PoCs	Persons of Concern
UNHCR	United Nations High Commissioner for Refugees

# 2. Objective

The objective of this document is to provide the United Nations High Commissioner for Refugees' (UNHCR) staff and implementing partners (IPs) with updated, specific and practical principles and guidance on how to plan and implement a country level health referral scheme for refugees, asylum seekers and other persons of concern (PoCs).

### 3. Definitions

#### 3.1 Primary health care

Primary health care (PHC) is classically defined as essential health care based on practical, scientifically sound and socially acceptable methods and technology made universally accessible to individuals and families in the community through their full participation, and at a cost that the community and the country can afford to maintain at every stage of their development in the spirit of self-determination (Alma Ata international conference definition, 1978). In practice, PHC components vary according to context but should be available at first-contact with the health system and on a continuous basis. It incorporates the tasks of medical diagnosis and treatment, psychological assessment and management, personal support, communication of information about illness, prevention, and health maintenance. Depending on the setting, PHC may be provided by a nurse, family physician or other type of health worker. In 2008, the World Health Organization advocated for a renewal of PHC taking into account that globalization is putting the social cohesion of many countries under stress, and health systems are clearly not performing as well as they could and should (www.who.int/whr/2008/en/index.html).

#### 3.2 Referral health care

Secondary referral health care is an intermediate level of health care that includes diagnosis and treatment performed in a hospital or health center having specialized personnel, equipment, laboratory facilities and bed facilities.

Tertiary referral health care is more specialized medical care for patients who are usually referred from secondary care centers. It includes subspecialty expertise in surgery and internal medicine, diagnostic modalities, therapeutic modalities for treating advanced and/or potentially fatal diseases (e.g. cancer). Very often, third (and/or fourth level) are linked with a university medical school.

The types of upper levels of care are usually defined by the Ministry of Health of each country in terms of specialisation of the services provided, staff profiles and complementary examinations. However, there is a need for UNHCR to look at official Ministry of Health levels of care that are, in some contexts, more theoretical and may not reflect the real operational capacities of hospitals. UNHCR must thoroughly assess the effectiveness, efficiency and quality of care in each circumstance, and this must be undertaken by health professionals. Please refer to the Public Health Facility Toolkit for *Assessing, Monitoring and Evaluating the Quality of Public Health Services Supported by UNHCR* for guidance (www.unhcr.org/cgi-bin/texis/vtx/search?page=search&docid=47c3dfce2&query=public%20health% 20facility%20toolkit).

#### 3.3 Persons of concern to UNHCR

According to the UNHCR handbook for emergencies, UNHCR identifies five main population categories collectively referred to as 'persons of concern to UNHCR' or PoCs. These include: (a) Asylum-seekers (b) Refugees; (c) Internally displaced persons (IDPs); (d) Returnees who are refugees and IDPs who return in their country of origin; and (e) stateless persons. Each region and UNHCR office defines its PoCs according to the humanitarian and political situation analysis. Please refer to the office's Country Operation Plan for specifics.

# 4. Introduction

The focus of UNHCR's protection and assistance health programmes is a combination of preventive and PHC that employs a public health and community development approach. Please refer to following site for the UNHCR's public health and HIV guiding principles and strategic plans (www.unhcr.org/publ/PUBL /488600152.html).

The PHC services are often grouped in packages. These packages vary by country and may sometimes appear long and confusing. Some packages focus on a specific target population, for example less than 1 years of age, under 5 years of age, women or pregnant women, while others target specific diseases such as human immunodeficiency virus (HIV), malaria or mental health. UNHCR endorses and advocates the Alma Ata declaration of 1978 PHC approach. The 2008 World Health Organization's World Health Report underlines and updates the needs and challenges for a renewal of PHC now more than ever (www.who.int/whr/2008/en/index.html).

However, one should not underestimate the humanitarian, political and economic importance of referral health care. PHC policy will neither be understood nor accepted by beneficiaries without a proper system to access care for more complex cases. If medical conditions cannot be managed at the PHC facility level, referral for emergency or essential medical, obstetric and surgical care to the nearest appropriate health care facility is required. While life saving emergency care is rarely subject to discussion or denied, the definition of what types of cases should be referred is commonly a source of debate and misunderstanding. These guidelines intend to provide basic principles, share acquired experience, take into account shortfalls in health systems according to different contexts, clarify frequent misunderstandings to avoid common problems, and identify gaps for further operational research.

The different settings of UNHCR's operations bring with them a wide variety of disease patterns and burdens. This document, therefore, provides broad principles and guidance. Practical decisions and details on standard operating procedures for health care referrals must be taken for each setting individually according to context.

## 5. Challenges

Establishing and managing a referral health care scheme presents many challenges:

- **5.1** The PHC approach is UNHCR's primary health strategy. Depending upon the context, funds and logistics, secondary and tertiary health care may not be given the same emphasis.
- **5.2** The budgets allocated to health assistance are often limited and difficult to fund. They never meet all of the health needs of the refugees and other PoCs. Therefore, providing sufficient care for costly and long courses of treatment for diseases such as cancers or kidney dialysis is difficult and prioritisation will be necessary.
- **5.3** Sophisticated and costly investigation procedures such as computed tomography scanning and magnetic resonance imaging are becoming routine in many countries for diagnosing and treating specific diseases. The pressure for accessing high technology investigations is increasing. The indication and benefits for these procedures need to be closely balanced and monitored by UNHCR and IP health staff.

- **5.4** Some countries lack qualified health care providers in the remote areas where UNHCR's PoCs are often situated to sufficiently oversee referral health care systems.
- **5.5** The access to and quality of health services can sometimes be better for refugees and other PoCs than for surrounding host populations. This inequity can create tensions and affect the protection of PoCs, especially during protracted and local integration scenarios.
- **5.6** Host Governments are often reluctant or lack the capacity to enforce legislation that provides refugees and other PoCs with similar rights to access health care facilities as those of national citizens. In situations where PoCs become entitled to treatment at Government health facilities, the additional strain on existing services might become a source of tension between locals and PoCs.
- **5.7** Even when PoCs have similar rights of access to services to those of nationals, they often lack the means to pay (e.g. if there is a co-pay requirement or payment is required for ancillary services, medications, or payment for travel to and from the referral facility). Furthermore, PoCs may have reduced coping mechanisms, linguistic barriers or other specific vulnerabilities that may make it difficult for them to access these services compared with nationals.
- **5.8** The uniqueness of refugee and other PoCs often requires health facilities to adapt to meet their needs (e.g. different languages and culture, specific vulnerabilities and protection issues).
- **5.9** UNHCR delivers health assistance throughout a wide range of contexts (e.g. urban-rural; camp-noncamp; emergency-post emergency; repatriation-resettlement-local integration) that evolve over time. Therefore, it is not possible to provide one referral health guideline that applies to all situations. For example:
  - In camps where medical assistance has been established *de novo* from PHC to the referral level, referral programmes are relatively more straightforward to establish.
  - In urban or rural scattered situations, PoCs and nationals are living intertwined and the focus should be to integrate them into existing systems.
  - Urban populations have the tendency to '*shop*' for health care regardless of the way the system is set up. The urban private health sector is varied, attractive and often considered better quality than public systems; however, it is generally more costly. In such scenarios, persons may '*skip*' the public systems completely or go directly to specialized services while not using PHC.
  - For durable solutions, such as voluntary repatriation and local integration, the scope of UNHCR's assistance can be uncertain in terms of timeframe and target group definition.
    For example, how long should UNHCR support a population that has become locally integrated in the host community? How long should UNHCR support health services in the country of origin after refugees have returned home?
- **5.10** Referral systems must also take into account local demographic characteristics and burden of diseases as well as the level of development of the host country's health system. This varies greatly between low income and middle income countries. Factors that must be considered include issues related to co-payment, specifics related to various diagnostic and treatment algorithms, and treatment of chronic diseases (e.g. diabetes, kidney insufficiency, cancers). The availability, capacity and cost of existing host country referral facilities are crucial.

## 6. Ten Guiding Principles

#### 6.1 Clear target group definition(s)

In all PoC situations, those benefiting from referral health care programmes must be clearly defined and agreed upon with appropriate Government authorities. This agreement should be properly communicated to all respective parties including Government public services, civil society and non-governmental organisations (e.g. some countries have not signed the 1951 refugee convention and, thus, are not bound by its principles. In such circumstances, persons that may fit the definition of a refugee may not be designated as such, and may not be provided with sufficient protection space or access to services).

#### 6.2 Primary health care is first level of care

PHC should remain the entry point for all medical referral. PHC aims to bring health care as close as possible to where people live and work. The PHC approach is based on community participation at a cost the community and the country can afford to maintain at every stage of their development. When PHC is substandard in terms of access, quality, bio-security or universal precautions to prevent the transmission of communicable diseases, UNHCR must advocate and build up partnerships to address these gaps as a matter of priority.

#### 6.3 Avoid use of parallel systems and build on existing structures

Whenever feasible, the use and support of existing national health systems for PoCs are recommended. Depending on the prevailing health system setting, referrals should be channelled through the national public health network and/or the private non-profit health service. In some settings, PoCs could be included in national health care systems if the system has the capacity to deal with the additional caseload in an adequate manner. UNHCR should work with its partners to improve the existing system's capacity whenever possible (e.g. rehabilitate health structures, and provide medications and trainings to clinics or hospitals in areas that are highly populated by PoCs).

When district or regional referral level of care is below international standards in terms of quality, bio-security and universal precautions, UNHCR should support and advocate among authorities and partners to address these priority issues, concentrating upon those that are most life threatening. Depending on their functionality, all advocacy and coordination bodies should be considered, such as UN Country Teams, UN health working groups, Joint UN team on AIDS, donor groups, etc...

#### 6.4 Equity of care and access between PoCs and host populations

UNHCR's Public Health and HIV guiding principles state that refugees and other PoCs should have a similar level of access to and quality of care to that of where they came from and to that of their local host populations.

In nearly all contexts, PHC as well as emergency treatment should be free for refugees and other PoCs to UNHCR. Referral costs will be covered by UNHCR according to standard operating procedures that must be created by UNHCR according to each country's specific context.

Assessments of the PoCs' ability to pay for referral health services should be conducted to assess whether cost sharing would be an appropriate strategy. In settings where health insurance is widely used among nationals, UNHCR can consider contributing to an insurance scheme for PoCs.

Sudan / Returnees Cecilia brought her son Alex Nomorro (2 1/2) to the hospital in Yei where he was admitted for severe malnutrition. UNHCR / M. Pearson / September 2005

In settings where host populations (or certain subgroups) do not have free access to PHC or referral health care, PoCs may have better access to health care than local residents. This could occur in urban, camp or rural settings, particularly for referrals from PHC facilities. Such inequity might directly affect PoCs' protection space. Therefore, strategies should be established by UNHCR and its partners to minimise this imbalance. For example, the facilitation of transport for local surrounding host populations who need an emergency medical referral could be provided.

In most situations, health policies and treatments for PoCs follow current Ministry of Health guidelines and protocols. However if national protocols are found not to be in line with international guidelines, UNHCR and its IPs will advocate for their use. The quality of equipment and supportive aids, such as wheelchairs and prostheses should generally not exceed that which is available to nationals in the same surrounding. This should also be the case for operations that cannot be performed in the host country. In general, refugees and other PoCs should only to be sent to a different country for treatment if this option is available to members of the host community.

Refugees who wish or decide on their own to purchase health care outside the health services developed by UNHCR must do so at their own expense. This may include accessing certain referral procedures or medications that are not paid for by UNHCR or accessing private hospitals that do not have an agreement with UNHCR.

#### 6.5 Referral is a medical decision

Referral care must be decided or cleared by a medical doctor. When there is an emergency and a medical doctor is not available, other health staff such as a nurse, midwife or other type of health worker can initiate the referral that should be cleared later by the medical doctor.

In operations where decision on referral cases and management becomes complex, costly or controversial, the medical doctor must design, lead and coordinate a transparent decision making process for health referrals with clear rules that are written down and publicly available.

#### 6.6 Referral decisions are primarily based on prognosis and cost

There are only two types of referrals:

Emergencies (obstetrical, medical and surgical) and

Elective cases for complementary investigations and/or specialised treatment

For both types of referrals, prognosis is the most important criteria. The prognosis determines the rationale to attempt to provide care for certain treatment(s). Prognosis must be assessed by a qualified medical doctor. Concomitant illnesses that affect prognosis need to be considered. For the most part, cases presented for health referral should be those where the life or basic functions of the PoCs are at stake. It is preferable to initiate medical referral at the early stages of illness when the prognosis has a higher probability of being favourable.

Cost of treatment will affect the possibility for referral as budgets are nearly always limited. Long lasting treatment programmes (e.g. dialysis, diabetes, some cancers) will require re-evaluation of the case on a regular basis. Particular attention must be given to the follow-up management of emergency cases. For example, if a patient with a stroke or heart attack is referred to a hospital in an emergency situation and is in the intensive care unit, a long term treatment plan together with

costs must be cleared by UNHCR. For emergency cases, it is advised that each country develops an agreed list of emergency case definitions and a list of institutions able to manage them.

Cases should not be referred for health care if the health of the patient has reached such an advanced stage of deterioration that survival or recovery is unlikely (e.g. cases of advanced renal failure, malignant cancers) or the condition has been treated correctly but unsuccessfully over a long period of time (e.g. corrected surgical cases with failed results). Such cases should continue to receive medical treatment, including palliative care when appropriate and available locally.

In operations where decisions on referral cases and their management become complex, costly or controversial, it is recommended to create a *referral committee* that will assess individual cases and make an objective decision about the referral based primarily on prognosis and cost. UNHCR's participation will ensure that the committee's decisions fit with referral principles, priorities, standard operating procedures, budget, and level of care.

This committee must be professional and independent in its decision making. The confidentiality of the patients' files must be protected. UNHCR's Public Health Officer is responsible for the establishment and composition of the committee. S/he will ensure coordination, documentation and follow-up including the provision of minutes for each meeting. The committee should be equipped with guidance on review criteria.

The composition of the referral committee depends upon the country setting. From experience and where feasible, a minimum of three health professionals is recommended to ensure a fair and transparent process that understands both the reality of health services in the country and has knowledge of the best evidence-based practices. In general, health care professionals that have direct contact with PoCs should not be part of the committee and the names of the members of the committee should remain confidential to avoid any undue pressure or influence. (See annex that provides an example of a referral committee's terms of reference). The referral committee may also be best placed to identify those relatively rare cases that are appropriate for medical resettlement to a third country.

It is recommended that the medical technical decisions based primarily on prognosis for the referral occur first and separately from those involved in making decisions based on finance. The latter should occur after the medical recommendations have been received.

A flow chart or diagram with different decision levels, at least for emergency referral care, should be developed.

# 6.7 Secure transparency of process through consultation, clear communication and widespread dissemination

UNHCR's country operations at all levels and all partners should be fully and clearly informed about the policy and procedures for health referrals including the limits of health assistance provided. A communication strategy that includes PoCs needs to be developed, implemented and disseminated widely.

In conflict situations, UNHCR and its partners must help to ensure that affected populations understand and support the rights of people to be protected and to receive care. The need to respect distinctive emblems, such as the Red Cross/Crescent should be emphasised so that persons being referred are transported safely and efficiently for the benefit of all.

UNHCR and its partners need to clearly know who is eligible for which level of health care service (e.g. registered refugees with official documents, asylum seekers, local populations, and/or other vulnerable groups). In conflict situations, special attention must be given to the dissemination of referral procedures among armed combatants.

It is recommended to create and disseminate a leaflet with a concise summary of referral guidelines for PoCs. The structure of the proposed leaflet should be drawn from the above guiding principles. Clear and transparent standard operating procedures, translated and communicated to the affected communities in their local languages can help manage expectations and explain the limitations. Furthermore, it would support the work and security of UNHCR and partner staff dealing directly with daily requests. Referral procedures should also be clearly communicated to all involved health staff.

In addition to disseminating information to the wider community on referral entitlements and eligibility requirements, clear communication and information should also be provided to individual persons to inform them of the decisions by the referral committee. This is required both in the case of acceptance and rejection. In cases of rejection, due consideration must also be given to the alternative forms of care that can be provided at the community level (e.g. palliative, hospice care, psychosocial support).

#### 6.8 Appropriate contractual agreements with service providers

Written agreements with hospital care service providers are necessary to clarify expectations, services that will be covered, ensure quality of care, and define types and guarantee of payments. It is an important document to monitor roles and duties among all stakeholders: PoCs, IPs, UNHCR and service providers.

An agreement should describe all referral procedures such as documentation, forms, official signatories, transportation modalities, medical file management, reporting, and payments. It should also record the approved cost of hospitalisation stay, cost of investigations and cost of treatment(s) based on official country level health sector documentation.

UNHCR recommends using Memoranda of Understanding and contracts. A Memorandum of Understanding is a simple agreement with a hospital that UNHCR and/or IP(s) support in terms of staff, medical supply or equipment in exchange for hospital care provided to the PoCs. It is a less legally binding commitment compared with a contract.

Contracts are more detailed and legally binding agreements that are requested when payment for hospital care is needed. A contract needs to consider at least the following information listed below:

	Background of project
Desc	riptive of services required by customer (IP, UNHCR)
	Definition of beneficiaries
	Type of services required
	Cost of services required
Oblig	gations of service provider (hospital)
	Acceptance of beneficiaries defined
	Quality of services provided
	Confidentiality/protection of beneficiaries (taking into account national law)
Oblig	gations of customer (IP, UNHCR)
	Notification of patient
	Transport modalities
	Payment of services provided
	Monitoring
	Reporting
Forr	n of payment (cash, in kind)
Pena	Ities if obligations not respected
Гime	of validity
Sian	atures

A single or limited number of partners present many advantages to UNHCR in terms of establishing agreements, securing protection and confidentiality, monitoring the quality of care, and adapting to the various cultural and language differences of PoCs. It also helps to negotiate, rationalise and monitor the costs.

Medical or surgical referrals will be preferably treated in public or private non-profit hospitals whenever possible. All costs of services including ancillary costs should be negotiated for beneficial rates. In general, UNHCR should negotiate with the hospital or Ministry of Health to provide the same rates as those given to the most vulnerable populations in the hospital's catchment area. Special fees for foreigners should not be accepted if proposed.

The respect of confidentiality of patients' medical files should be closely monitored by UNHCR's Public Health Officer or another officer designated by UNHCR. Experience has shown that administrative exchanges within and outside UNHCR can breach confidentiality. Serious attention needs to be given to better protect patients' confidentiality, privacy and dignity.

The agreement should be established among UNHCR's IP(s) and the referral facility with UNHCR (as a tripartite agreement) or with UNHCR signing on as a witness with possible quality, quantity and performance control co-authority along with other involved Government bodies.

#### 6.9 Coordinate with prevention programmes

Causes of health referrals need to be analysed to coordinate with prevention and early screening programmes. If such programmes do not exist, UNHCR should work with the Government and other partners to advocate for their establishment. For example, cancers and cardiovascular disease should be linked with anti-tobacco and life hygiene campaigns while malaria should be linked with long lasting insecticide impregnated net distribution and use campaigns. The character of this effort will depend on the disease patterns in different settings. Cases that can be treated early or perhaps even avoided will provide great benefits for persons and result in less strain on resources and health care systems.

For prevention efforts to succeed, functioning and adequate secondary and tertiary levels of health care are necessary. Where national screening and prevention programmes are in place, UNHCR and its partners should advocate for the inclusion of refugees and other PoCs.

#### 6.10 Explore all possibilities for referrals

Medical cases requiring treatment exceeding UNHCR or national capacity may benefit from other humanitarian channels, particularly if there is a positive prognosis. Health networking is essential to create linkages with other assistance avenues. Each country should explore opportunities for self-reliance for cases that require life long treatment.

Some opportunities may be in the form of disease specific programmes such as surgeries for cleft lips, vesico-vaginal fistulas, cardiac and cataracts. In some contexts, charitable organisations, nongovernmental organisations, private sponsoring agencies within the country or the region may be a possibility. Furthermore, approaching Embassies of various Governments may lead to different opportunities.

Medical resettlement also presents an opportunity whose feasibility and success must be assessed and reviewed with UNHCR Protection colleagues. However, the chances of medical resettlement are very small relative to the number of referred cases. Clear medical referral standard operating procedures should be established in each country. These will lead to efficient use of UNHCR and partners' resources and time as well as avoid false expectations from PoCs. As mentioned above, referral committees are efficient and effective ways of identifying appropriate cases for possible medical resettlement.

### 7. Monitoring and Evaluation

UNHCR and its partners are required to monitor referrals in order to ensure proper follow-up of referred patients, quality of referral care as well as the efficient management of resources. The monitoring and evaluation of referral systems should be integrated into the standard operating procedures to ensure compliance with data collection and information sharing requirements.

#### 7.1 Initial assessment:

Right from the start it is essential to assess referral settings and providers. When setting up a referral system, it s required to assess 1) access; 2) availability; 3) quality; and 4) cost of diagnostic and therapeutic procedures. For more information on assessing referral systems, see the UNHCR Facility Assessment Toolkit (www.unhcr.org/cgi-bin/texis/vtx/search?page=search&docid=47c3dfce 2&query=unhcr%20 facility%20toolkit).

#### 7.2 Monitoring framework

A referral information system should be established to monitor the performance of the referral programme and to ensure proper and continued medical follow-up of referred cases. Ideally this can be integrated within a broader health information system that is used to monitor the wider public health programme. The standardised UNHCR camp-based health information system provides basic functionality in this respect.

Referral information systems should record information at the point of referral and from the referral care provider. In order to ensure that data are collected at both points in the referral process, the information system should be set up in a way to facilitate data on the outcome and cost of referrals that *'return'* or come back to from the referral centre to the PHC centre and are fed into the monitoring system. One method to do this is to link the payment of referral invoices to the requirement of reporting back on the outcome of the referral. Where this option is not feasible or where referrals are free-of-charge, the *'referral note'* (patient's referral document) should consist of a discharge section (where the outcome and follow-up recommendations are recorded by the physician) and can be used for monitoring purposes.

For timely follow-up and resource management, the monitoring system for referrals should follow a monthly reporting cycle. As with all monitoring systems, regular feedback should be provided at all levels of the system.

#### 7.3 Referral care indicators

At a minimum, the referral information system should collect aggregate data on the number of referrals, the place of referral, the reason for referral, the outcome, and the cost. Depending on the setting, more advanced information such as the outcome and the cost of each referral, and more detailed age and sex disaggregation, needs also to be collected; this will require case-based information systems to be designed. Due consideration must be given to data protection and confidentiality issues for such systems that hold individual medical data. In operations where an IP is designated to manage referrals, it is that IP's responsibility to collect and collate these data from the various points of origin. The distinction of aggregate and individual level data requires different monitoring tools.

#### 7.4 Cost of referrals

When setting up a referral system, available procedures, capacities and their associated costs should be mapped and shared among stakeholders involved in the referral system; this will ensure predictability as well as transparency and control of costs. This issue is of particular importance when the referral system has a budgetary ceiling, and expensive interventions are managed by a referral committee or board that needs to make difficult decisions as to who will or will not receive care.

#### 7.5 Evaluation

Referral systems should be evaluated at regular intervals and at minimum, annual evaluations should occur. Monitoring data feed into the overall evaluation process, and will contribute vital information as to the performance and efficiency as well as resource management and determination of resource requirements. The latter is of particular importance within the programme planning cycle in which resources are being allocated to different programme activities.



## Conclusions

UNHCR's principles and guidance for referral health care need to be adapted according to the diverse contexts and environments in which UNHCR works. Every referral programme will have specific standard operating procedures according to its specific context. These need to be clearly defined and communicated to all beneficiaries and stakeholders. Referral hospital care management remains primarily a medical programme that involves medical and non-medical actors. It must be supported at the country level by UNHCR's Senior Management Staff taking into consideration the necessary medical leadership and confidentiality issues.

In all PoC situations, those benefiting from referral health care programmes must be clearly defined and agreed upon with appropriate Government authorities. PHC should remain the entry point for all medical referral. Whenever feasible, the use and support of existing national health systems for PoCs are recommended.

Prognosis of emergency and elective referrals is the most important criteria from the medical perspective. For the most part, cases presented for health referral should be those where the life or basic functions of the PoCs are at stake. However, cost of treatment will affect the possibility for referral as budgets are nearly always limited. In operations where decisions on referral cases and their management become complex, costly or controversial, it is recommended to create a referral committee. Medical resettlement, although not applicable at a large scale, remains an opportunity for cases with a reasonable prognosis. The referral committee may also be best placed to identify those relatively rare cases that are appropriate for medical resettlement to a third country.

A written agreement with hospital care service provider(s) is necessary to clarify expectations, specify which services will be paid for, ensure quality of care, and define the types and guarantee of payments. Legal contracts are recommended with all institutions where UNHCR pays for services. The quality control of sub-contracted hospital care remains UNHCR's concern and must be included and monitored within the written agreement. Due to the nature of administrative procedures that accompany referral care clearance and payment, special attention to medical file confidentiality is needed throughout the process.

A functioning and regular monitoring system for referral care is a prerequisite for evidence-based decision making. Referral information systems should record information at the point of referral as well as from the referral care provider.

Referral health care needs are constantly evolving due to increasing urbanisation, ageing refugee populations with a concomitant disease epidemiological shift from infectious to chronic diseases, and the increasing technical sophistication of hospital care. Referral care represents an important humanitarian component of protection and assistance programmes where UNHCR allocates substantial financial and human resources. Such essential programmes need to be carefully monitored and evaluated to ensure that accessible and quality services are available to the largest number of PoCs at a reasonable cost.

Pakistan / Peshawar Khyber teaching hospital. Zarin takes care of his 2-year-old son Navid who suffers burns since a bomb fell on their home in Balogram, in Swat Valley. Navid's sister, Zaida, also sustains burns on her face. Since early May, 2 million people have been displaced from Swat, Lower Dir and Buner districts following conflict between militants and governmental forces. UNHCR / H. Caux / June 4, 2009

1

# Annex: Example of Terms of Reference for a Referral Care Committee

**Objective:** To ensure a fair, equal and cost-effective treatment of patients requiring referral care.

**Rules and procedures:** The Committee is guided by the rules and procedures on medical/health care as stipulated in country referral standard operating procedures.

**Committee membership:** The Committee should be comprised of a Chair (i.e. UNHCR Doctor) and two members (two independent external doctors) and one Secretary. Technical experts or other resource persons can be invited upon request of the committee to clarify and explain specific issues to the Committee. The names of the committee members shall only be known to the Representative of UNHCR to avoid pressure and possible harassment. The UNHCR Exceptional Care Committee can also be used as a screening tool for possible medical resettlement cases.

**Quorum:** The Committee requires participation of the Chair/alternate plus two members in order to meet and take decisions.

**Tenure of the referral committee:** The Committee shall be established on the 1<sup>st</sup> of January of the year for a period of 12 months (ie. until 31<sup>st</sup> December). The frequency of the meetings shall be discussed and decided by the committee based on the number of cases that require a decision. This decision shall be recorded in the terms of reference.

#### The core roles of a referral care committee include:

- Meeting regularly to review newly submitted cases according to identified needs and prognosis of the proposed intervention
- Ensuring a transparent, efficient and cost-effective selection process
- Reviewing regularly previously submitted cases to monitor progress and take appropriate action when required (e.g. continuation or discontinuation of the treatment)

#### The core roles of Committee members include:

- Being conversant with the individual cases, local health standards and procedures and the selection criteria of the committee
- Reviewing all documentation submitted in order to form an objective opinion for the selection of new cases
- Reviewing all documentation submitted in order to form and objective opinion on the progress of existing cases and possible decision for continuation/discontinuation

# Under the guidance of the Chairperson, the secretary is responsible for the following specific tasks:

- Receive new cases, number sequentially and ensure documentation is complete, including necessary supporting documents
- Notify Committee members, or their alternates, of the day, time and place of the meeting, and get confirmation of attendance to ensure quorum
- Circulate agenda including all submissions to be discussed during upcoming meeting with supporting documentation not less than 3 days before scheduled meeting
- Take minutes during meeting, accurately noting major points of discussions and precise decisions
- Provide draft minutes of meeting within 2 days and distribute to committee members for any comments and corrections
- Have corrected minutes signed by Chairperson and other two members within 3 days of meeting
- Maintain confidential file with all minutes of meetings and supporting documentation

#### Key criteria for accepting patients are:

- Prognosis of disease including concomitant illness that would effect treatment of disease for which the patient was referred
- Cost of complete treatment

#### **Referral procedures for referral care review:**

- Patient file must be completed and include all appropriate diagnostic results as well as prognosis
- Concomitant illness(es) that could effect treatment of disease for which patient was referred is clearly stated
- Financial statement of UNHCR-designated Government hospital on cost estimate of prescribed treatment from start to finish or annual cost if this is treatment for chronic disease that requires treatment for more than one year

These terms of reference are a template adapted from the field. It needs to be adapted according to each country's context based on the needs, requests, access and availability of referral health care.

# **Annex: Glossary and standard definitions**

**Designated Health Professional:** In the framework of the referral system, the Designated Health Professional is the person who is allowed and in a position to recommend and authorize medical referrals.

- For emergency cases it is the health professional on duty e.g. the midwife on duty for emergency obstetric referrals.
- In other circumstances, it is generally the most senior health staff (e.g. medical doctor, clinical nurse, clinical officer). Designation of alternates is needed during Designated Health Professional's absence from duty station.

**Emergency cases:** An emergency case refers to a medical condition where the prognosis (immediate or long term) can be improved by a medical or surgical intervention accessible through referral and where time is a determinant factor.

**Elective cases:** A case whose health condition would benefit from a secondary or tertiary care treatment but time is of less important to the outcome

**Prognosis:** The prognosis predicts the outcome of a disease and therefore, the likely future of the patient. The prognosis is good when it is expected that the patient will either recover fully or his/her health or his quality of life will significantly improve.

**Primary Health Care (PHC):** Essential health care based on practical, scientifically sound and socially acceptable methods and technology made universally accessible to individuals and families in the community through their full participation and at a cost that the community and the country can afford to maintain at every stage of their development in the spirit of self-determination" (Alma Ata international conference definition)

**PHC package:** Refers to a set of norms and standards. It defines the core health and health-related interventions to address major health problems and disease conditions of the country. These preventive, promotive, curative, and rehabilitative interventions are considered to be the minimum that people can expect to receive through the various health delivery mechanisms and facilities with in their reach.

• PHC packages are country specific, ususally defined by the Ministry of Health

**Secondary Health Care (SHC):** This is an intermediate level of health care that includes diagnosis and treatment performed in a hospital or health center having specialized personnel, equipment, laboratory facilities and bed facilities.

• What type of services included in SHC are country specific

**Tertiary Health Care (THC):** Tertiary health care is more specialized medical care that cannot be performed at primary and secondary levels. It includes subspecialty expertise in surgery and internal medicine, diagnostic modalities, therapeutic modalities for treating advanced and/or potentially fatal diseases (e.g. cancer).

• What type of services included in SHC are country specific

Cover Photo: Kenya / Dadaab's medical teams are already overstretched, and with the coming floods there are fears of a cholera or malaria outbreak, which pose considerable health threats to the refugees and would be difficult to contain in such crowded conditions. © Australia for UNHCR / T. Mukoya / October 2009

Public Health and HIV Section Division for Programme Support and Management December 2009

