NCD care in humanitarian settings: a clarion call to civil society

This document was originally shared as a briefing and an introduction to the Bootcamp “Mobilizing young leaders within civil society for advocacy on NCDs in Humanitarian Settings” which was held in June 2018 – a partnership between the Danish Red Cross, IFRC, NCDFREE and the University of Copenhagen.

This document draws on desk research, a literature review and 14 expert interviews, with quotes from those interviewed indicated in *‘italics’.*

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NCD FREE

A NEGLECTED CRISIS

Non-communicable diseases (NCDs) are the leading cause of death globally, with three-quarters of this mortality occurring in low- and middle-income countries. However, NCDs have been largely unrecognised and inadequately addressed – particularly in humanitarian crises. This is a significant, urgent opportunity to improve the health of some of the world's most vulnerable people living in some of the world's most fragile settings.

"Tackling NCDs in humanitarian situations is a missing piece"

– Sigiriya Aebischer Perone, ICRC

The extent of humanitarian crises

Humanitarian crises result from conflict, war, natural disaster or a combination of factors (known as complex emergencies). An estimated 134 million people will be affected in 2018, of whom many will be forced from their homes: there currently are around 25.4 million refugees, 3.1 million asylum seekers and a further 40 million internally displaced people globally. Today, a higher number of refugees and displaced people live among host communities than in refugee camps.

Humanitarian crises cause displacement and breakdown of systems and society, with serious impacts on health systems: infrastructure, supply channels and the health workforce come under intense pressure. Stages of emergencies range from emerging crises and acute emergencies, through to chronic situations and post-crisis situations in which recovery can begin to take place. And many emergencies are becoming increasingly protracted, with the average length of displacement due to conflict now more than 17 years. Short-term responses are no longer sufficient.

The impact of crises on NCDs[+]

As worldwide demographics (aging populations), environments (unhealthy diets, tobacco use etc.) and epidemiology (the increasing NCD burden) change, humanitarian emergencies will increasingly occur in populations who are already at high risk of NCDs – particularly diabetes, hypertension and cardiovascular disease. This began to be evident in the 1990s in the Balkans and among Palestinian refugees, continued in the Middle East and Sudan in the 2000s, and is very clear today, particularly in Syria and surrounding countries.

The traditional humanitarian response to managing the acute phase of an emergency (dealing with trauma, injury and infectious disease) is by nature short-term and reactive – but a longer-term, comprehensive approach is needed to address NCDs. Conditions that have in the past been successfully managed with little impact on daily life can rapidly deteriorate and lead to complications.

"The provision of continuing medication in a crisis situation is just as essential as the provision of surgery"

– Sigiriya Aebischer Perone, ICRC

There is a striking lack of appropriate financial and practical support for NCDs in emergencies and only limited evidence on what is most needed. However, one study suggests that heart attack and stroke are 2–3 times more common after an emergency than before, and another found a 180% increase in visits to the doctor for asthma. Among the 4.6 million people who are now refugees from Syria, diabetes is estimated at 7.4% and hypertension at around 25%. Among older Syrians in Lebanon, one study found that 47% reported having diabetes.

Where resources are severely constrained and there is very limited possibility of ongoing care, difficult ethical choices must be made around screening and which conditions to treat. Cancer treatment, in particular, is often simply too costly to be a priority in an emergency – but palliative care should be available.

Prevention of NCDs will become increasingly important to prevent the deterioration of long-term health among the world's growing displaced and refugee population. Many will not be able to return home for years and will struggle to access treatment and care, with poor living conditions (poverty, unemployment and a lack of access to healthy food) also reducing the capacity of individuals and families to cope.

The Sustainable Development Goals call on all countries to achieve a 30% reduction in deaths from NCDs among those aged 30–70 by 2030, but this will not be achieved without a new, comprehensive approach to addressing NCDs in humanitarian crises. Civil society has not, to date, played a concerted, coordinated role in bringing NCDs in humanitarian situations on to the global health agenda: it's time this changed!

"We need to move beyond rhetoric and awareness to concrete solutions"

– Pablo Parel, London School of Hygiene and Tropical Medicine

Why are people living with NCDs particularly vulnerable?

- NCDs require continuous care over extended periods of time, often necessitating treatment with medication or other medical technology (supply chains for which may be severely restricted) and sustained interaction with healthcare workers (who may no longer be available).
- When routine care is disrupted, people living with NCDs become more susceptible to acute complications, requiring additional treatment and expense.
- Coordination of care between different healthcare workers and settings is crucial, particularly for people with more than one health condition (co-morbidity) – but may be impossible in crisis situations.
- NCDs may limit the ability of individuals and their families to cope with the emergency.

Source: Draws on the WHO / UN Inter-Agency Task Force on NCDs.

+ For a succinct introduction, see WHO / UN Inter-Agency Task Force on NCDs, Non-communicable Diseases in Emergencies (2016).

GAPS AND CHALLENGES

Highlighted in this document are six key areas that, together, could greatly facilitate an improved response to NCDs in humanitarian crises: access to treatment; continuity of care – people on the move; addressing risk factors in the community; preparedness; research and evidence; and financing and partnerships. The nine case studies presented in this document is meant to support and exemplify the key areas.

Access to treatment

In humanitarian crises, access to treatment for NCDs is severely disrupted. This extends far beyond access to medication: it is about how health systems under serious stress can ensure continuing, affordable access to drugs/diagnostics/tools, referral for specialist treatment, and health workers.

For the first, acute phase of an emergency, the World Health Organization has developed the Interagency Emergency Health Kit (IEHK) containing medical supplies to temporarily support a population of 10,000, drawn from WHO's essential drugs list. However, this did not fully take into account the burden of NCDs, and it is only recently that an NCD Kit (see Case Study 1: WHO EMRO NCD Kit) has been developed to begin to *'build the bridge'* [Slim Slama, WHO EMRO] between initial crisis and longer-term support for people with NCDs. However, the Kit can only ever be transitional: a longer-term response is needed.

Even where existing national guidelines on diagnosis, treatment and care exist, they may be unworkable in an emergency. The draft SPHERE Guideline 2018 provides overall guidance in an emergency (although this contains only a short section on NCDs – see box) but there is a need for simplified, validated protocols and guidelines explicitly for NCDs – such as those developed by humanitarian organisations such as MSF and PCI. An operational guideline is currently being developed that will cover diabetes, hypertension, cardiovacular disease (CVD), asthma and chronic obstructive pulmonary disease (COPD), include palliative care, and reference existing mental health guidelines (MHGap). But there is currently no one standard guideline for addressing NCDs in humanitarian crises.

An important barrier to equal access to treatment, identified in the literature review[1], is the high cost of NCDs. Out-of-pocket expenses include medication, treatment and screening (particularly where health care is privatised), travel (particularly to access specialist care, often further from home) and healthy food. One study found that only 3 per cent of elderly Syrian refugees in Lebanon had sufficient funds

to buy medicine, and when Jordan brought in a form of co-payment for refugees in 2014, this pushed the cost of treatment out of reach of many refugees. Low-cost 'humanitarian' pricing of quality drugs should be sought.

In a fragmented health system, there may be a vertical approach to care, in which each disease is treated independently. NCD care should be integrated into primary health care services in the community, bringing together support for physical NCDs with mental health and infectious disease (see Case Study 2: MSF primary care and boxes below) An approach that can be effective in providing integrated access is to use mobile health clinics. These can deliver services where medical infrastructure has been damaged, going into local communities (as far as possible at a regular time and place) to provide care in patients' own neighbourhoods (see Case Study 3: IRC and mobile health clinics).

When refugee populations are housed in host communities, tensions can arise if the two populations have access to separate healthcare systems: running parallel systems is inequitable and not sustainable in the long run.

The absence of trained health professionals – whether community health workers or specialists – is also a particular concern. Displacement and high turnover of healthcare staff in emergency situations mean that experience and capacity are frequently lost.

NCDs in SPHERE

Key action 1:
Identify the health needs of the disaster-affected population with regard to NCDs and determine availability of NCD services pre-disaster

Key action 2:
Implement NCD programmes using a phased approach based on life-saving priorities and relief of suffering

Key action 3:
Ensure integration of NCD care into health systems at all levels to help continuity of care

Key action 4:
Establish prevention and preparedness programmes for NCDs

An example: Insulin

Cold chain for medication is a particular concern – although it is now recognised that insulin can be safely stored in clay pots for months, and does not, in fact, require refrigeration.

Even where insulin is available, patients may not have access to glucometers, so cannot check their blood sugar and adjust doses (and food intake) accordingly.

[1]The development of this document was supported by a literature review conducted by University of Copenhagen (see notes at the end)

CASE STUDIES

1

WHO EMRO NCD Kit
– Iraq and northern Syria

The WHO Global Action Plan on NCDs 2013–2020 called for the deployment of 'an inter-agency emergency health kit for treatment of noncommunicable diseases in humanitarian disasters and emergencies', and WHO EMRO recently took the initiative in developing this, to complement WHO's Interagency Emergency Health Kit (IEHK).

The new Kit avoids duplication of supply with the IEHK, while retaining enough capacity not to be dependent on supplies from other kits. The medicines follow guidance both from the Package of Essential Noncommunicable (PEN) Disease Interventions for Primary Health Care in Low-Resource Settings and the Mental Health Gap Action Programme. Medical equipment is also included, such as glucose strips, syringes and glucometers.

The new Kit is flexible enough to be used in primary-health centres, mobile-health clinics or field hospitals. It is modular and can be ordered by sub-module, based on country needs and capacities. A monitoring framework has been designed, with an electronic platform and mobile apps that enable the use of the Kit to be monitored remotely.

The Kit began to be rolled out in northern Syria and Iraq in October 2017 and 39 kits were distributed in the first six months, and 227 Syrian staff trained on their use. It is hoped that its successful deployment will allow the Kit to be used as an advocacy tool, demonstrating the impact of cost-effective interventions and to encourage donor funding for NCDs in humanitarian crises.

2

MSF primary health care
– Jordan

A vertical primary-level NCD programme has been designed and is run by MSF-OCA in Irbid – the city in Jordan with the second largest number of Syrian refugees after the capital Amman. The initiative, which was initially a pilot, serves a cohort of approximately 4,000 Syrian refugees and members of the Jordanian community. It began in 2014 and addresses three of the primary NCDs focused on by WHO: cardiovascular disease, diabetes and chronic lung disease (it does not currently address cancer or palliative care). Patients have a consultation with a physician and individual health education sessions with a health educator. Blood pressure and blood sugar measurements among those who stayed in the programme for 6–12 months have improved (more detailed results have not yet been published).

The programme has evolved and continues to do so. Mental health and psychosocial services have since been added, because it quickly became clear that the burden of morbidity was too great to focus only on physical health, and a humanitarian liaison offer has been appointed to look at protection and poverty issues – both major drivers of health. There are also moves towards task-sharing with nurses for stable patients. A partner NGO provided referral services such as retinopathy screening, but this was discontinued, as it was dependent on short-term donor funding.

Continuity of care – people on the move

Ensuring a continuum of care for people living with NCDs is always a challenge because NCDs require lifelong support. In crisis situations, this is greatly exacerbated: displaced, transient populations often have to move between health facilities or humanitarian agencies, making it harder both to access and provide care.

Refugees generally need identification papers to access health care in their new countries. But many lose these on route, leaving them for months or years without the medical care required to manage a chronic disease. Even registered refugees in camp settings often lack access to specialised and reliable care.

In many crisis situations, only outpatient care can be provided, with no scope for registration and follow up with patients. There is an urgent need for a robust system of patient follow-up, facilitating the transfer of documentation and medical records. However, passing information between health facilities, humanitarian agencies and between countries is made even more complex by the need to protect and secure sensitive patient data. A mapping of healthcare facilities across borders could also help to facilitate continuity of care and transferral of information.

Healthcare workers will often have to rely on patients' own recollection of their medical needs, where other sources of health information are not available. Patient education and knowledge of self-care are particularly important, as patients will not be able to turn to their health records for information on their treatment. Helping patients to understand and adapt to new circumstances is also crucial. For example, in the Middle East, patients may previously have been treated in specialist settings with specific medications, and therefore may be reluctant to switch to primary-care settings and being provided with cheaper (generic) drugs.

Where there is very limited possibility for continuity of care, difficult ethical choices must be made around which conditions to treat. Cancer treatment, in particular, is often simply too costly to be a priority in an emergency – *'cancer care is almost impossible'* [Sigiriya Aebischer Perone, ICRC] – although pain relief and palliative care should be available. Screening, too, may be inappropriate and unethical if there will not be the treatment available to follow up. However, a rights-based approach to health requires that the needs of the most vulnerable should always be prioritised – and this includes refugees and displaced people living with NCDs.

Addressing risk factors in the community

As the acute phase of an emergency (during which provision of essential treatment is the priority) gives way to a protracted crisis, the longer-term challenges of living with and prevention of NCDs need to be addressed, involving patients, families and local communities.

It is a false distinction to separate out physical NCDs from mental-health conditions: particularly in humanitarian crises, mental and physical health go hand in hand, and the co-morbidities and need to integrate care must be recognised. Psychosocial support provided by civil society and humanitarian organisations is a core part of patient support, self-care and disease prevention.

The need to integrate physical and mental health is acknowledged and acted upon by MSF's 2016 Programmatic and Clinical Guidelines on NCDs, which contains a chapter on psychiatric conditions. In an emergency, trauma, violence, displacement, poverty and isolation can cause mental-health conditions including post-traumatic stress disorder and depression, which are linked with hypertension and CVD.

"NCD care cannot be delivered without addressing the mental health and humanitarian needs of the population"

– Éimhín Ansbro (London School of Hygiene and Tropical Medicine)

The stigma that can surround NCDs may also have repercussions for mental health and social isolations (see Case Study 4: Diabetes outpatient care).

Refugees and humanitarian workers may have a mindset of transience: that the situation will abate, and life will return to relative normality. However, the reality is that the crisis may last for years – so taking action on prevention of NCDs is required. While many of the WHO's 'Best Buys' on NCDs may not be feasible in an emergency situation (for example, legislation on tobacco or high-sugar/salt products), preventive actions are possible in partnership with humanitarian organisations and communities – for example, in nutrition (see box).

Population based screening is not recommended in an emergency due to ethical concerns over not being able to deliver the appropriate care. But in relatively stable pockets or camp settings, community mechanisms can be used to promote healthy lifestyles and care-seeking behaviour: it is local communities – where and with whom we live, learn, work and play – that are 'the first line of defence against NCDs' [Daniel Zoughbie, Microclinic International] (see Case Study 5: Microclinics for Palestinian refugees).

But while there are examples of local social networks – for example, patient groups or expert patients (see Case Study 6: Patient support in Dadaab refugee camp) – helping to empower self-care and facilitate adherence to medication, support healthy choices and improve mental health, these are not standard practice and are not integrated into emergency response. Involvement of the local community, and listening to people living with NCDs, will also facilitate the delivery of services in a way that is culturally appropriate and acceptable, including palliative care.

Example: Nutrition

In emergency situations, adequate food must be provided to prevent malnutrition.

Food distributed in emergencies may be high in calories and not sensitive to specific needs of people with NCDs is – e.g. availability of reduced sugar products for people with diabetes.

Dietary advice can be very hard to follow, because of lack of access to and means to buy appropriate food

Nutrition has an intergenerational aspect: maternal malnutrition and a lack of breastfeeding are both risk factors for NCD in babies' later life.

3

IRC and mobile health clinics
– Syria, Yemen and Libya

The International Rescue Committee provides mobile health clinics in Syria, Yemen and Libya. Each clinic is a van containing medicines for a wide range of health conditions including NCDs, accompanied by a range of staff: doctors and nurses, and perhaps midwives and pharmacists.

The clinics visit specific communities on a schedule (as far as is possible in an emergency situation) and at a regular location, such as a school or an old health facility that is no longer in use. But the care provided cannot be as comprehensive as that provided in a static facility, and is focused primarily on heart disease, hypertension and diabetes. Most tests are rapid, as the circumstances proscribe anything more complex. A static facility is also preferable because it allows for more treatment of a wider range of conditions, and provides continued access to care and more consistent follow-up, whereas the mobile health team may have nowhere to which to refer patients. In Yemen, the government has requested that IRC put more emphasis on supporting static health facilities, as it is a more sustainable approach and provides better continuity of care.

However, mobile health clinics can reach people who may not otherwise have any access to health care: in Syria in 2017, four mobile health clinics run by the IRC reached 29,015 people, of whom around 14.5% per cent received treatment for NCDs.

4

Diabetes outpatient care
– DRC

In the Democratic Republic of Congo, a Ministry of Health local referral hospital that MSF had been supporting for eight years saw increasing numbers of patients with diabetes. There were also serious issues around stigmatisation of diabetes: *'According to some patients, being diagnosed with diabetes was a more traumatic moment than being diagnosed with HIV. The latter is "just a pill", whereas diabetes means having to eat special meals away from your family, ostracisation, and possibly even amputation'* (Kiran Jobanputra, MSF).

In response, MSF established a formal diabetes outpatient scheme: the Integrated Diabetic Clinic within an Outpatient Department (IDC-OPD). Physician involvement was limited to initial and six-monthly checks and specific referral criteria, with the project being primarily nurse-led, with support from a nutritionist, a psychosocial support officer, and counselling staff with locally appropriate counselling materials. Patient files were formalised, and patients given their own health 'passports'. Costs per patient are comparable to that for chronic HIV care at €183–415 per patient per year.

5

Microclinics for Palestinian refugees
– the Middle East

Since 2015, the UN Relief Works Agency for Palestine Refugees (UNRWA) been rolling out a Microclinic model of NCD care for people living in refugee camps in Jordan, Gaza, the West Bank and Lebanon. So far, the programme has trained over 1,059 healthcare workers, with 114,134 programme participants who act as health ambassadors, focusing on the 'four Ms': medication, meals, movement and monitoring. Collectively, these ambassadors have reached over half a million people.

The rationale behind the programme is that health is contagious. MCI is rethinking public health in terms of the sociology of a disease, not just its biology. Educating individuals about health will not make a sustainable difference unless their surrounding social and physical infrastructure also support necessary changes in lifestyle: *'This programme is all about civil society – thinking about healthcare infrastructure as more than bricks and mortar. The most important part of the infrastructure is people and groups of people'* (Daniel Zoughbie, Microclinic International).

A forthcoming study of the impact of the programme in 115 UNRWA health centres in Jordan, Lebanon, Syria, the West Bank and Gaza evaluated the impact on 1,000 participants. Groups of participants, along with their social network, attended sessions, over which time weight loss, blood sugar reductions, and improvements in blood pressure were achieved. Levels of trust between patients and health workers have also increased, which can serve to strengthen the health system as a whole.

6

Patient support by Red Cross in Dadaab refugee camp
– Kenya

The Dadaab refugee complex in Kenya is one of the largest in the world: a population in 2017 of almost 240,000 registered refugees and asylum seekers. In one camp with a population of around 65,000, where the NGO burden is estimated at 2.3 per cent, the Kenyan Red Cross has been working with around 40 community health workers to provide NCD drugs and services to over 450 people: 313 receive treatment for hypertension, 78 for diabetes, 23 for asthma and 16 for CVD. Among the main laboratory services offered are blood sugar testing and liver and kidney function tests, and medication offered include insulin and metformin.

In additions, wider social networks are actively involved. Patients are encouraged to join one of 17 support groups, each led by a community health worker, which provide health information, nutrition counselling and psychosocial support. In addition, an estimated 1,700 people have been reached through community-based sessions (including awareness of the NCD risk factors) and ensures that the local population understand the community health system. 20 community health workers have been provided with peer-educators training, and 10 primary schools have been visited for NCD education sessions. Lessons are shared with an NCD working group committee made up of the International Rescue Committee, MSF, the Kenya Red Cross and UNHCR.

Preparedness

Rapid action in an emergency can save lives but is dependent on effective pre-planning. Emergency preparedness is action taken to address the risks, build capacity and prepare for humanitarian emergencies, to reduce the effects of any future crisis on the population. It should specifically address the needs of vulnerable groups such as people living with NCDs.

However, NCDs are a relatively new priority for national health systems in countries that have undergone rapid epidemiological and demographic change, and so NCDs are often not adequately included in local and national preparedness plans: *'Business-as-usual is not enough!'* [Slim Slama, WHO EMRO].

A key element of preparedness is access to accurate, up-to-date data from prior to the emergency – without this, it will not be able to estimate the needs of people living with NCDs or to predict future trends. An understanding of the capacity of the health system to manage NCDs in an emergency is also essential (for example, how referrals could take place from primary to secondary care level), and preparedness plan should also include efforts to ensure the supply chain of essential medicines, perhaps including stockpiling of medication appropriate to the needs of the local community.

Health workers – both in-country and from humanitarian organisations – should be trained in the knowledge, skills and capacity to diagnose and treat NCDs in emergency situations. And local communities can also be educated and empowered to be more resilient in an emergency, ensuring that people living with NCDs and disabilities have the knowledge and tools they need to manage their condition, and also that local social networks understand their needs and can support them in an emergency, particularly if evacuation is required.

Research and evidence

In many low- and middle-income countries, there is little reliable granular data available on NCDs – and this is magnified in humanitarian crises. Pragmatic, standardised data-gathering systems are needed that can be used in these fragile settings. Evidence is needed to identify, prioritise and advocate for effective interventions.

The review of peer-reviewed literature found just 40 articles on NCDs in humanitarian settings, and the standard of data is both poor and patchy: people with NCDs remain undiagnosed, many studies are reliant on self-reporting, data-gathering tools are not designed to capture NCDs and their risk factors, and health workers may have neither the knowledge, capacity nor equipment to gather the data that is needed.
Few studies compare pre- and post-crisis situations. There may be ethical concerns around whether research should even be a priority in situations where there are many unmet humanitarian needs. And of course, in emergency settings data-gathering may be close to impossible

Of the major NCDs, diabetes receives the most attention, addressed in 21 of the 40 studies. 13 addressed cardiovascular disease (including hypertension), nine addressed cancer (which is particularly challenging to treat in emergencies), and only four on chronic lung disease such as asthma. None addressed air pollution but, as the literature review noted, household and ambient pollution are major contributors to global mortality, and where people are living in cramped settlements with only basic cooking and heating facilities they may be more likely to be exposed to indoor pollution.

There is a particular lack of operational research and evidence of effective interventions. Although – as the case studies demonstrate – there are ongoing initiatives to tackle NCDs in humanitarian settings, one systematic review found no studies existed in 2015 on these types of interventions.

The financial burden of NCDs in crisis situations is also unclear. A recent report by WHO, *Saving Lives, Spending Less,* has clearly set out the financial burden of NCDs in low- and middle-income countries – but does not look specifically at humanitarian crisis situations. Given that these crises are becoming more extensive and increasingly protracted, the long-term economic effects of failing to address NCDs will have increasingly severe repercussions for individuals, communities, health systems and economies.

Traditional research has required high standards of data quality and time that may not be available in crisis situations. More flexible methodologies, and smart use both of grey literature and existing data, are required. Experience also shows that there is the potential for digital technology to assist in responsive and accurate data management (see Case Study 8. Dharma mobile data-gathering platform). The NCD Kit also allows for improved data capture and easy-to-use mobile apps can be used both within health clinics and by community health workers (see Case Study 7. An mhealth app).

Financing and partnerships

Innovative financing and new ways of working are required for NCDs worldwide, and particularly in humanitarian situations. A recent *Lancet* report has highlighted that 'the notable lack of enthusiasm by global health donors has made it especially difficult for lowest-income, donor-dependent countries to even assess the size of the health burden' for NCDs.

Sustained funding and treatment is crucial for those living with NCDs in humanitarian emergencies –but NCDs in protracted crises too often fall between short-term humanitarian funding and development assistance for health (less than 2 per cent of which is allocated for NCDs).

Action on NCDs requires a whole-of-government, whole-of-society approach – but to date much of the international focus on NCDs has been on international political commitments, rather than on national action. The scaling up and extension of addressing NCDs in lower-income or emergency situations – achieving the right to the best available standard of health for all – can only be achieved through improved financing and new partnerships.

International agencies and funders are coming on board – the FDA, World Bank and ECHO (European Civil Protection and Humanitarian Aid Operations), for example – but more funding and resources are needed. The George Institute in Sydney is looking at a social enterprise to bring fixed-dose combination drugs into broader use. Partnerships between local civil-society organisations and international agencies can be successful – for example, the 'training the trainer' approach of PCI, working with organisations including the WHO, MSF and UNHCR (see Case Study 9: Training the trainer). Defeat NCD is a another new partnership which includes a strand of work on NCDs in emergencies.

The WHO also recognises that partnership can include the private sector, although this can be time consuming and requires taking careful steps to avoid conflicts of interest. The ICRC, Danish Red Cross and Novo Nordisk have also recently (2018) launched an initiative to address diabetes in humanitarian emergencies, addressing a mapping of the current landscape, ensuring availability of medicine and supplies, developing field projects to address treatment and prevention of NCDs, improve monitoring and evaluation – and advocate for change.

7

An mhealth app – Lebanon

In 2015–16, Johns Hopkins University ran a pilot study in 10 primary health care centres in Lebanon (supported by the International Organization for Migration and the International Medical Corps) to look at the effectiveness of treatment guidelines and an mhealth application on the quality of care and health outcomes. Patients were primarily refugees from Lebanon and Syria.

The mhealth approach had positive benefits. Recording of BMI and blood pressure were greater than recorded in clinic medical records, lifestyle counselling increased, and satisfaction with clinic visits improved significantly, with 95 per cent of patients feeling they were involved in consultation and treatment decisions (up from 69 per cent at baseline).

However, the application was used in less than a quarter of consultation, with a perceived barrier being that documentation requirements were not integrated with existing systems, requiring duplication of effort. The app must be as simple to use as possible and ongoing technical support provided.

The Massachusetts Institute of Technology, Johns Hopkins University and the IRC are now developing and piloting an app for use by community health workers (CHWs) – taking mhealth outside health facility while maintaining mhealth support for NCD consultations at health-facility level. This will help CHWs to document and report their work, make it easier to access data, and will help to measure the effectiveness of community NCD work, while also ensuring that patient treatments are tracked. Development and deployment of this app will consider lessons learned from the Lebanon pilot and existing tools currently in use by CHWs in humanitarian settings.

8

Dharma mobile data-gathering platform – Syria

The Dharma mobile platform is a health surveillance programme that facilitates the collection of baseline and follow-up information, including on NCDs. Information is gathered through a structured interview, training for which is quite straightforward, which is entered on a tablet.

In one example in south Syria, training on the platform was done by Skype, and data collection took place over five days, covering 1,000 households (over 4,000 people), including questions on access to health care and food security, on self-reported disease (lung disease, hypertension, diabetes etc.). It found that 50 per cent had some sort of NCD – which is vital information in assessing the drugs that are required in the local population. The work also made clear that there is a need for a more community-based response. This does not create an electronic medical record for individuals; the data is anonymised, and can be used to track supplies and manage projects on the ground. It has been used to track the shipment of NCD Kits (see Case Study 1) from The Netherlands to Turkey and Turkey to Syria

The advantages of the mobile platform are speed and simplicity of data collection (no coding is required) and analysis (which takes a third the time of analysing data records), and it is easily accessible (the information can be shared in real time around the world).

CIVIL SOCIETY

Tackling NCDs in any situation requires a strong, coordinated approach – and this need for partnership comes into even sharper focus in humanitarian crises. No single agency, government department or NGO can solve this, and it requires the full involvement of civil society.
Over the last few years, humanitarian organisations have begun to address the need to tackle NCDs in crisis situations as they have reacted to the realities on the ground. International agencies, too, are taking action: the UN Inter-Agency Task Force on NCDs has established an informal working group that is drawing up operational guidelines and a set of key indicators.

But this is happening far too slowly. The need for immediate action needs to be clearly stated, and a clear, coordinated message sent to other key partners, including donors:

"NCDs are 70% of mortality globally but are not included in the humanitarian response. This doesn't make sense!"

– Slim Slama, WHO EMRO

The HIV/AIDS epidemic demonstrated how crucial the role of civil society can be in directing the global response to a crisis, and there are many lessons to be learnt from previous experience that can be used to push this agenda much more widely – including giving a much greater voice to people living with NCDs.

The involvement of young leaders – from academia, the NCD and humanitarian worlds, the media and across civil society – can have a profound effect over time. Not only are they best placed to understand the concerns of youth populations, but the knowledge and skills that they acquire will be used extensively in the future, in whatever career path they choose to take.

Civil society is not yet fully cognisant of the extent of the NCD issue in humanitarian settings but is well placed to raise awareness on the problem among policymakers (advocating for well-directed projects) and donors (advocating for well-directed and well-funded initiatives), and to create new partnerships.

So, the question is: how to raise awareness among civil society and among young leaders in particular, and how can civil society then take the call for action forward?

A CLARION CALL

2018 is a year of opportunity: a High-Level Meeting on NCDs is to be held during the United Nations General Assembly in September, and there are increasing demands that care for people with NCDs should be a core component of calls for Universal Health Coverage.

Civil society must join together in a clarion call for action to extend the focus on NCDs to include humanitarian situations. People living with NCDs are among the most vulnerable within already vulnerable populations and must not be neglected either in the acute crisis or in longer-term responses.

If human rights are to be respected and fulfilled, and the Sustainable Development Goals achieved, support for people living with or at high risk of developing NCDs in humanitarian crises must no longer be allowed to fall through the gap.

9

Training the trainer – Middle East and Africa

Primary Care International (PCI) has been partnering to provide front-line doctors, nurses and community health workers with the clinical knowledge and skills, consultation and communication skills, NCD clinic management and related systems strategy needed to tackle NCDs. The initiatives take a 'training of trainers' approach: training techniques for cascading training to others.

In the ongoing Caring for Refugees with Non-Communicable Diseases project in refugee camps in seven countries in Africa, NCD champions are identified who will train other health workers in the camp, and work with in-country UNHCR public health officials on the roll-out of NCD action plans. The project also incorporates coaching and continuing professional development activities to support these NCD champions to effect change.

In 2017, PCI worked to co-deliver training in NCD management to MSF clinicians from across the organisation and collaborated in the creation of e-learning resources for a much larger number of clinicians to manage NCDs in MSF clinics around the world.

As a partner to WHO, in 2017 PCI adapted NCD guidelines to the Syrian context and delivered a number of 'training the trainer' sessions in support of these guidelines for doctors working inside Northern and Southern Syria. Training has since been cascaded to more than 100 clinics in the country. Doctors have also been trained in the use of WHO NCD Emergency Kits; these include PCI's NCD Field Guides, which help to ensure that the Kits are used efficiently and effectively (see Case Study 1).

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THE PARTNERS

Danish Red Cross (DRC)

The DRC supports vulnerable people to live safe and healthy lives in humanitarian and development settings as well as in Denmark. The DRC equips people with the tools they need to strengthen their resilience. The DRC supports people on both sides of conflict and in the remotest corners of the world with a special expertise in community-based health services. NCDs in humanitarian settings is a key priority in DRC.

NCDFREE

NCDFREE is a crowdsourced global social movement dedicated to getting NCDs on the map of young people everywhere through creative campaigns and social media engagement. Since its founding in 2013, NCDFREE has hosted 11 advocacy Bootcamps to spread awareness and identify solutions for reducing the global burden of NCDs.

University of Copenhagen

Driven by intellectual creativity and critical thinking since 1479, researchers and students at the University of Copenhagen have expanded horizons and contributed to moving the world forward. The School of Global Health, University of Copenhagen, acknowledge NCDs as a major challenge in humanitarian settings and strive towards making a difference for the communities impacted by NCDs through strengthening human resources, advocacy and research partnerships aimed at identifying novel and effective preventive, curative and rehabilitation strategies to combat the major NCDs.

The International Federation of Red Cross and Red Crescent Societies (IFRC)

IFRC is the world's largest humanitarian organization, providing assistance without discrimination as to nationality, race, religious beliefs, class or political opinions. Founded in 1919, the IFRC comprises 191-member Red Cross and Red Crescent National Societies along with 12 million volunteers, a secretariat in Geneva and field delegations strategically located to support activities around the world. IFRC carries out relief operations to assist victims of disasters along with development work to strengthen the capacities of its member National Societies. The IFRC's work focuses on: promoting humanitarian values, disaster preparedness and response and health and care.

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