**INSPIRATION AND ASPIRATION:** 

# Advocating for NCD care in humanitarian settings

OUTCOMES OF A BOOTCAMP JUNE 2018

Civil society – including researchers, NGOs, the private sector and local communities – has a significant role to play in heightening understanding and increasing action on Non-Communicable Diseases (NCDs) in humanitarian settings. This document is the outcome of a Bootcamp, held in June 2018. It brought together young professionals and experts from civil society to inspire advocacy action on the challenge of NCDs in humanitarian settings. We hope that readers will take inspiration from the discussions, policy asks and campaign ideas and turn them into reality.

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### Contents

- 4. At a glance
- 6. A neglected crisis
- 8. The Bootcamp
- 9. Participants' reflections and take-aways
- **1**0. Access to treatment: 'Good intentions are not good enough'
- 12. Continuity of care people on the move: 'An obstacle course'
- 14. Addressing risk factors in the community: 'Invest in health, not disease'
- 18. Preparedness: 'A massive social justice issue'
- 20. Research and evidence: 'From data to decisions'
- 22. Financing and partnerships: 'Invest in best buys leave no one behind!'
  - 24. Common threads
  - 26. Final word

The Bootcamp was developed and hosted by the partners:







### At a glance



million people currently affected by humanitarian crises

68,5 **Mittal** 

million are refugees or displaced persons



3/4 of NCD deaths occur in low- and middle income countries

#### The challenge...

...is the striking lack of political focus, funding and support for treatment, care and prevention of non-communicable diseases (NCDs) in emergency settings, despite the huge burden imposed by these conditions on the 134 million people currently affected by humanitarian crises.

#### The Four major NCDs



Diabetes



Cardiovascular disease



Chronic respiratory disease

#### A Bootcamp

...brought together 70 young professionals and established experts from more than 30 different organisations to inspire advocacy action on the challenge of NCDs in humanitarian settings. *"Working in the field, I was at first hesitant when I heard I had to focus on NCDs – but after understanding and seeing the need for it, I now realise how important it is"* 

- Bootcamp participant

#### The outcomes...

...of the Bootcamp were six policy asks, supported by ideas for campaigns that civil society could take forward to advocate for the policy asks:



#### Access to treatment

We call on WHO to develop guidelines for NCD care in humanitarian settings, ensuring consistency and quality of care.



#### Continuity of care - people on the move

We call on member states to fund WHO and partners to develop a secure, personalised, mobile health data system for humanitarian settings, building on new technology.



#### Addressing risk factors in the community

We call on governments and humanitarian actors to systematically plan for and resource NCD prevention before and during humanitarian crisis.



#### Preparedness

We call on all governments to develop an action plan to respond to the needs of people living with NCDs – and people at risk of developing NCDs – in the event of a humanitarian crisis.



#### Research and evidence

We call on the WHO Global Coordination Mechanism on NCDs to establish a free, online, open-source Hub to connect funders, researchers and humanitarian actors.



#### Financing and partnerships

We call on WHO to develop 'best buys for NCDs in humanitarian settings'.

#### Finally...

The Bootcamp also led directly to a **Call to Action** to civil-society experts attending the UN Interactive Hearing on NCDs in early July 2018, requesting them to make the case for the inclusion of NCDs in humanitarian settings in the UN Political Declaration on NCDs:

"We call on all those with influence over the negotiations on the Political Declaration—including Ministries of Health, Country Missions at the UN in New York, and civil society leaders—to raise the issue of NCDs in humanitarian crises as a major and growing health threat to some of the world's most vulnerable populations and ensure its inclusion in the Political Declaration. If we are genuine in calls to provide Universal Health Coverage and to "leave no one behind", NCDs in humanitarian crises simply cannot be ignored."

### A neglected crisis

An estimated 134 million people will be affected by humanitarian crises in 2018,<sup>1</sup> of whom 68.5 million are refugees or displaced persons. In 2017 alone, 16.2 million people were displaced, either for the first time or repeatedly.<sup>2</sup> This means that one in every 110 people in the world today has been forced from their homes.

Emergencies are becoming increasingly protracted, with displacement sometimes measured in decades. The traditional humanitarian response, however, is short term and reactive, responding to the acute phase of the emergency. Chronic conditions and long-term prevention planning are therefore not part of the response. There is a striking lack of political focus, funding and support for treatment, care and prevention of NCDs in emergency settings, despite the burden that they pose on communities. Successful prevention, care and treatment of NCDs has economic benefits for families, business and society, reduces loss of life and upholds the right to health – and is absolutely necessary to address if governments are to reach their Sustainable Development Goal commitments of a 30 per cent reduction in premature mortality from NCDs by 2030. People affected by emergencies are among the most vulnerable populations in the world, so if calls for Universal Health Coverage are serious, then their needs must be prioritised.

2018 is an important year for NCDs; September sees a High-Level Meeting on NCDs during the United Nations General Assembly in New York – an opportunity for heads of state and government to recognise and commit to the need to act. The impact of humanitarian crises on NCDs must not be neglected.

This report presents the policy asks, discussions and ideas developed at the Bootcamp. The suggested policy asks are not at all exhaustive but the result of two intense days aiming at mobilizing young leaders within civil society for advocacy on NCDs in humanitarian settings.

Both the policy asks and the campaign ideas supporting the policy asks in this report are meant as an inspiration for your own advocacy.

Civil society –researchers, NGOs, the private sector and local communities – has a very significant role to play in heightening understanding and increasing action on NCDs in humanitarian settings. We encourage everyone not only to read this report, but to take the ideas and turn them into reality.



### The Bootcamp

People working in the humanitarian, development, global health, academic and advocacy fields do not often get the chance to meet, share their thoughts and break down barriers between the disciplines. The NCDs in Humanitarian Settings Bootcamp, held in Copenhagen over two days in June 2018, brought these disciplines together, mixing the enthusiasm and innovation of early-career professionals with the wisdom of operational experts with longer experience.

The Bootcamp brought to life a wish to think the challenge afresh by bringing local civil society and young leaders to the forefront of the policy dialogue on NCDs. The Bootcamp was inspirational, aspirational and practical – asking what needs to be done, identifying new pathways to achieve this, and ensuring a role for civil society.

At the end of the event, participants;

- achieved a shared understanding of the specific challenges related to NCDs in humanitarian settings and felt inspired to address them,
- developed bold policy asks and campaign ideas to further a policy agenda on NCDs in humanitarian settings and,
- forged new networks and partnerships as a platform for joint advocacy efforts.

#### What we did at the Bootcamp

The Bootcamp was designed to ensure an engaging and inspiring environment with 'TED Talk'-style presentations held by experts and practitioners, and breakout sessions, where participants worked in smaller groups.

Six key areas formed the basis for the breakout sessions in the groups: Access to treatment, Continuity of care, Addressing risk factors in the community, Preparedness, Research and evidence, and Financing and partnerships.

The participants discussed challenges related to each key area and their vision for change. Based on these initial discussions they developed policy asks and presented these to the other participants and advocacy experts for input and feedback. They framed the policy asks within supporting campaign ideas that could be used by civil society to take the agenda forward.

At the final day of the Bootcamp, the policy asks and campaign ideas were presented to a high-level panel of decision makers and an advocacy expert – the Danish Ministry of Foreign Affairs, the IFRC, the World Health Organization (WHO) and Advice – to qualify the outputs.

#### Participants' reflections and take-aways

"Young people are the ones who have to deal with this problem in the future, so they should be the ones to bring the solutions." - Jared Nyamongo, head of advocacy, Young Professionals Chronic Disease Network Nairobi

*"I have always wanted to be a medical doctor working with humanitarian issues and I had always through about that as primarily infectious diseases – but I think my view on that has changed quite dramatically over the last few days."* 

- Troels Boldt Rømer, President at the Danish Red Cross Youth

"The really exciting thing for me today [was] not just to hear from a medical perspective but to hear from people who are in communications, who have done lots of work in policy. Both types of expertise are important to have an impact at scale." - Julia Beart, Head of Operations, Primary Care International

"By coming to this space together to talk about our challenges ... we are suddenly able to recognise that we are all facing the same challenges – and just that recognition ... allows us also to understand that these shared challenges can only be dealt with communally."

- Carlos Grijalva Eternod, Research Associate, University College London

*"It's been very tangible – we haven't been discussing things for the sake of it! We've been coming together and thinking of new ways to really move forward the agenda."* 

- Daniel Elliot, Partnerships analyst, UNOPS

*"I personally had never thought of what happens to people in humanitarian crises – I was always more focused on NCDs generally and how it affects people on a day-to-day basis in normal life. So it brought up a new mindset for me and new thoughts."* 

- Jared Nyamongo, head of advocacy, Young Professionals Chronic Disease Network Nairobi



### Access to treatment: 'Good intentions are not good enough'

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, consistent, affordable access to diagnostics and tools (as well as drugs), referral for specialist treatment, and retaining qualified health workers.

#### What? A policy ask

We call on WHO to develop guidelines for NCD care in humanitarian settings, ensuring consistency and quality of care.

#### Why? The rationale

There is a huge opportunity to improve access to treatment for NCDs, because the gap in provision is so large. The development of guidelines for care would lead to a more coordinated and standardised approach across different agencies, focus research appropriately, improve continuity of treatment offered to people living with NCDs, and encourage the provision of appropriate training for health professionals.

A focus of the guidelines should be building capacity of existing staff, with new training in NCDs in humanitarian emergencies and be based on a practical approach task shifting away from doctors towards nurses and community health workers: 'Why are nurses just an assistant to the doctor? There are so many things they could easily do!' (Bootcamp participant). The guidelines should also contain a section on how to adapt and prioritise care in different humanitarian settings.

Specific guidelines could also give donors and the private sector a clear rationale for investing in NCD treatment.

#### Discussion

Operational and contextual challenges – security issues, devastated infrastructure and disruption to supply chains – have serious repercussions for access to NCD treatment in humanitarian settings. However, these are usually beyond the control of humanitarian and health organisations; instead, the discussion centred on technical challenges, because *'within the technical area, we can change things!'* (Bootcamp participant). There is a real need for a standard but flexible set of guidelines that can be consistently applied.

"Good intentions are not good enough in humanitarian settings"

Guidance on how to implement the guidelines will be needed: *'Inventing the guidelines is the easy part: implementation is the difficult part!'* (Bootcamp participant). And, while the guidelines should be flexible enough to be adapted to different circumstances, they should not be

<sup>–</sup> Panu Saaristo, IFRC

so flexible as to no longer be meaningful and effective.

Another specific policy ask was also discussed: to improve health-seeking behaviour by including communities and people living with NCDs in the development of health promotion and service design. Stigma, discrimination and cultural barriers in accessing services can all be addressed through thoughtful, co-created design of programmes. "The guidelines would provide the means for agencies and ministries to provide a more consistent quality of care for our patients"

- Bootcamp participant

#### How? Campaign ideas

The campaign would focus on advocating for guidelines on NCD care in humanitarian settings with WHO as the agency responsible for setting standards and developing technical guidelines in health. A central part of the campaign would be to demonstrate the inconsistency in current NCD care practice in different humanitarian settings as well as the low standard of care in humanitarian settings in comparison with more stable settings.

Ideas for campaign elements include:

 A video containing short interviews with individuals – both medical staff and patients – from different humanitarian settings to illustrate the variations in practice and capacities, i.e. patients would be asked where they access insulin and doctors would be asked how to diagnose diabetes and what kind of protocols they use.

- Through research, the contrast between NCD complications in stable and in humanitarian settings could be explored and highlighted.
- With diplomatic efforts member states should be encouraged to ensure that WHO prioritise the development of guidelines, for example through statements at the High-level Meeting on NCDs (September 2018) and at the World Health Assembly in 2019.



### Continuity of care – people on the move: 'An obstacle course'

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

#### What? A policy ask

We call on member states to fund WHO and partners to develop a secure, personalised, mobile health data system for humanitarian settings, building on new technology.

#### Why? The rationale

There is currently no cross-border system in place for people on the move or living in protracted emergencies, with patients relying on paper records that are often inaccessible, incomplete or destroyed – and, even where they are available, are in a language unfamiliar to health professionals in the host country. There is a clear need to move from a system-based approach – as systems are often broken – to a person-centred approach, increasing patients' knowledge and capacity, empowering them to better manage their own health (avoiding the prescription of multiple drugs for the same condition, for example), and smoothing the transition into a host country.

Now is a good time: new, innovative technologies such as Blockchain could be utilised to facilitate secure, reliable access to patient data.

#### Discussion

Privacy issues are a major concern: who would hold, own and store the data? Confidentiality is essential if patients are to trust the system – for example, if patients access their files through fingerprint data and governments can manage to gain access to this information, it could be used to identify and deport refugees: there needs to be a strong firewall in place. But once patient trust is established, this trust will follow them across borders, easing the transition into a new health system.

"People on the move need help to negotiate 'the continuity of care obstacle course!"

– Bootcamp participant

The data may ultimately need to be integrated within the host country's system – hence, longterm compatibility should be considered when designing the system. The complexity of information management is paradoxical in an era of such effective information technology. However, the use of innovative technology could appeal to existing initiatives – for example, in Silicon Valley – which could lead to new, fruitful partnerships.

*"Treatment of NCDs needs to have a person-centred outcome and approach"* 

- Bootcamp participant

#### How? Campaign ideas

This campaign focused on influencing WHO indirectly through a member state: Denmark due to its 'global leadership in NCD care and research'. The Danish Ministry for Foreign Affairs (MFA) would be an appropriate specific institution to target as IT technology/diplomacy and public-private partnerships feature prominently in the Danish Strategy for Development Cooperation and Humanitarian Action and links well with existing initiatives, e.g. the Danish tech-ambassador in Silicon Valley.

Ideas for campaign activities include components of awareness raising and partnership-building:

 A pop-up event at the political festival Folkemødet in 2019, outside MFA's office, or to coincide with the High-Level Meeting on NCDs in September 2018, would create awareness about the challenges in ensuring continuity of care in humanitarian settings. This event would give the opportunity to interact with and hear the voices of health workers and displaced people living with NCDs, building a clear, empathetic narrative around the need for action.

- Interested civil society activists and private sector partners could write an open letter to the Danish MFA, calling for its active involvement in developing a secure, personalised data system for people living with NCDs in humanitarian settings.
- Partnerships could be strengthened and formed through incubator sessions: bringing together the tech-sector, civil society and government agencies to consider how such a system could be designed and implemented.

The campaign could be extended to other countries and development agencies (such as Department for International Development (DfID) in the UK), and give them the opportunity to showcase their own technology.



### Addressing risk factors in the community: 'Invest in health, not disease'

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 preventing NCDs need to be addressed – involving people living with NCDs, their families and local communities.

#### What? A policy ask

We call on governments and humanitarian actors systematically to plan for and resource NCD prevention before and during humanitarian crisis.

#### Why? The rationale

Current responses to humanitarian crises are often siloed, fragmented, short term, and strongly medicalised rather than community based. Other priorities may appear more pressing, particularly when coupled with a shortage of human and financial resources. Addressing the risk factors (poor nutrition, lack of exercise, smoking, alcohol and stress) using models of preventive action in humanitarian settings have not, to date, been a focus for researchers and humanitarian agencies. However, prevention and planning save lives during and beyond the acute phase of a crisis.

Success would be defined as NCD prevention being better resourced and fully embedded in regional preparedness plans, ensuring that those at risk of NCDs are included in an emergency response and mitigating the impact of a humanitarian emergency on the longer-term health of the population.

We need to create a strong basis that *'allows communities to be resilient and with the ability to withstand shocks'* (Bootcamp participant).

#### Discussion

The policy ask was welcomed by the experts but acknowledged as 'ambitious' because prevention is seldom prioritised enough, even in non-emergency settings – but 'realising this in emergency settings could be leapfrogging, doing the completely unexpected!' (Bente Mikkelsen, WHO). Prevention is possible in protracted crisis/refugee settings – for example through improved nutrition, psychosocial and peer support.

Although humanitarian funding is seldom available for prevention in general ('we are not peace-builders – we come in when things go wrong' – Panu Saaristo, IFRC), there needs to be a continuum between emergency response and longer-term preventive initiatives. Development stakeholders, and particularly donors, also need to be convinced of the benefits of engaging with and financing this agenda.

<sup>&</sup>quot;A complete 'change of mindset' is needed!"

Bootcamp participant

Several other actions were discussed that could maximise the potential for prevention of NCDs in humanitarian emergencies, including:

- taking a community-led and people-centred approach to promoting and implementing NCD interventions;
- investing in the generation of evidence from the implementation of non-medicalised interventions to address NCD risk factors; and
- creating a global platform for multisector coordination to ensure a comprehensive response to NCDs that includes prevention.

#### "We need community input as to what will really work!"

- Bootcamp participant

#### How? Campaign ideas

Building on the presence of Bootcamp participants from Kenya, the below campaign actions would aim at high-level civil servants in the Ministry of Health in Kenya, with advocacy efforts led by the Kenya Red Cross. However, the central campaign idea, to demonstrate the high cost in lost productivity and human lives if NCDs are not prevented, would be readily adaptable to other contexts. 'The government needs to invest in NCDs and create a platform where communities are resilient' or in short: 'Invest in health, not disease!' Specific ideas for campaign actions included;

- Set up site visits for government officials during natural disasters for example flooding, so that they can hear the stories first-hand of people living with NCDs and the challenges they face in these situations.
- Mobilise community voices the network of 'change agents': community leaders, politicians, health workers, religious leaders – to advocate for NCD prevention and preparedness.
- Build an investment case with research, showing that preventive efforts work and documenting the cost-effectiveness of different prevention packages versus treatment.

"Over 68.5 million people have been forced to leave their homes and all their belongings due to unstable living conditions – but something they can't leave behind is the burden of NCDs!"

- Bootcamp participant





### Preparedness: 'A massive social justice issue'

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.

#### What? A policy ask

We call on all governments to develop an action plan to respond to the needs of people living with NCDs – and people at risk of developing NCDs – in the event of a humanitarian crisis.

#### Why? The rationale

All the evidence suggests that NCDs are low on the list of health priorities before, during and after humanitarian crises. This is compounded by weak coordination between health actors, little clarity as to where responsibility for health lies (from local up to national level), and a failure in emergencies to focus on anything other than short-term, acute issues.

Every country should be prepared for disaster – and a preparedness plan will help mitigate the negative impacts, should the worst happen. NCDs must be fully integrated into preparedness, both nationally and internationally. This should also be a core part of planning for and delivering Universal Health Coverage.

Prevention is even less of a priority than treatment of NCDs – but good preparedness should also include consideration of how to prevent those at risk of developing NCDs (and related complications) in an emergency.

#### Discussion

The definition of 'preparedness' is a particular challenge: preparedness for what, for whom, and by whom? It covers community capacity, health system capacity and awareness raising (among local communities and political leaders) and must be contextualised to a range of settings, at the level of the individual, local community, national health system or even globally. The private sector can also be encouraged to integrate NCD prevention measures into its partnerships on NCDs.

International leadership is needed – but there must be national ownership of the plans. A small number of at-risk countries spearheading this approach would demonstrate the difference that effectively executed plans could make in practice. The plan should be adequately resourced and specify the roles and responsibilities of government, civil society, local communities and other stakeholders. There are lessons to be learnt from the HIV experience. For example, healthsystem resilience increased when there was a switch from requiring patients to access health facilities daily to a system under which larger stocks of medicines could be supplied. This is both more convenient for patients, but also increases the effectiveness of the system when supply chains are temporarily disrupted. Other strong ideas from the Bootcamp included:

- a call for partnerships between NGOs, research institutions and donors to trial interventions and identify best practice on improving NCD prevention in at-risk populations, prior to and during humanitarian crises; and
- a call for all humanitarian responses to include NCD prevention and treatment – such as providing healthy food in malnutrition programmes and including sports activities in social programmes.

#### How? Campaign ideas

The primary stakeholders for the policy ask are national governments, which would be required to develop the preparedness plans. There is also the opportunity for individual ministers and influencers to take the initiative and call on the World Health Assembly to adopt the suggestion. The practical, on-the-ground delivery of the plan during an emergency, however, would be dependent on a much broader set of stakeholders, including NGOs, health workers and community-based organisations. Therefore, the campaign actions must involve both the national government leadership and civil society:

 A punchy 'elevator pitch' by civil society on the extent of the NCD burden in humanitarian settings would lay the groundwork for speaking to ministers of health. This pitch would inform ministers about the urgency of tackling NCDs in humanitarian settings – 'this is a massive social justice issue' – and highlight the positive benefits of knowing how to respond to an emergency. Pressure from health ministers could help in bringing this forward as a priority at the World Health Assembly.

- Governments will however not address NCDs in humanitarian settings without the support of civil society. NGOs (covering all NCDs, including mental health) need to advocate strongly for preparedness plans, developing powerful stories that convey the urgency of action and create a positive narrative about what preparedness can achieve.
- Finally, if messaging about preparedness were to be delivered at opportunities such as the UN High-Level Meeting in September 2018, this would give a mandate to governments to push for rapid and effective action in this area.



### Research and evidence: 'From data to decisions'

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.

#### What? A policy ask

We call on the WHO Global Coordination Mechanism on NCDs to establish a free, online, open-source Hub to connect funders, researchers and humanitarian actors.

### Why? The rationale

There are well-documented and significant gaps in research in NCDs during humanitarian crises, with little data and research capacity available, and with a disconnect between research and needs on the ground.

Too often, evidence-gathering is not an integral aspect of NGOs' response to a crisis and the appetite for research into NCDs in humanitarian settings has been limited. There is a mismatch of interests between humanitarian organisations, often not concerned with research and publication, and academia, which is very strongly focused on the need to publish.

A platform is needed to share ideas and to identify what research is being done and where more effort is needed to bridge this gap, bringing together the right researchers, humanitarian actors and donors. Currently 'there is no one-stop-shop to find information' (Bootcamp participant). This will help to avoid duplication of effort as well as facilitating much better exchange of information about what works.

#### Discussion

Current research ideas are very linear and new ways of collecting and sharing data are needed. For example, the difficulties of ensuring credibility for 'anecdotal evidence' (Bootcamp participant) was acknowledged – how can this be published and acted upon?

The proposed platform would be a form of social media: connecting people with similar interests, facilitating conversations and the sharing of information and research, and demonstrating the benefits of collaboration to researchers and humanitarian actors who are looking for effective partnerships. It would also make clear to potential funders the need for investment in high-quality, cross-sector research that is both innovative and based on local need.

<sup>&</sup>quot;This would be a 'dating hub for projects!"

<sup>-</sup> Bootcamp participant

The vision underpinning the Hub is that all NGOs working in humanitarian settings are mandated and assisted to incorporate research into their regular activities. Separating research and action is to do both a disservice: they should go together.

Research will validate the need to prioritise humanitarian NCD action, and guide how this action can be most effective. This will then demonstrate clear fiscal incentives for funders to invest – both in collaborative research that is based on grassroot need, but also in initiatives that have been proven to have positive health outcomes. Funders may currently regard projects in humanitarian settings as too high risk because of political, logistical or security concerns – and this could give them the confidence to support longer-term initiatives. We need an NCD revolution – changing the way people think about NCDs, and making the case for more funding, research and action!

"A global alliance for generating evidence ... is very compelling in a world where everyone is asking for evidence"

- Panu Saaristo, IFRC

#### How? Campaign ideas

The stakeholder responsible for establishing the Hub- and the target of the campaign- is the WHO Global Coordination Mechanism on NCDs, which receives support from the WHO's Collaborating Centres around the world. These Centres could host the Hub in turn, which would ensure global ownership. The technology sector would assist in the design and delivery of the Hub, and the users are researchers, donors and humanitarian actors.

The campaign focuses on the Global Coordination Mechanism as it has a multi-sectoral mandate and existing initiatives such as the Knowledge Action Network, which includes repositories of information on various topics links up well with the idea of a Hub. This goes beyond a library and will become a *'marketplace of ideas – let's do it together'* (Bente Mikkelsen, WHO).

A short campaign video was produced at the Bootcamp, using humour to highlight

the need for a free, online, open-source Hub to connect funders, researchers and humanitarian actors

By linking all the key constituencies including researchers, government, funders, and people with NCDs in humanitarian settings, this calls on the WHO Global Coordination Mechanism to take action on three key areas:

- better connection of issues and solutions;
- improved collaboration on and sharing of information and resources; and
- scaling evidence-informed initiatives that can create change.

The campaign message will centre on answering the question: 'I have so little time and so little resource: on what should I focus and how should I do it?' To encourage WHO to act, storytelling and humour at a multi-partner launch at World refugee Day 2020 was proposed.



### Financing and partnerships: 'Invest in best buys – leave no one behind!'

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.<sup>3</sup>

#### What? A policy ask

We call on WHO to develop 'best buys for NCDs in humanitarian settings'.

#### Why? The rationale

Calls for cross-sector partnership align with Sustainable Development Goal 17: 'Strengthen the means of implementation and revitalize the global partnership for sustainable development.' Different sectors have complementary strengths; for example, the private sector is in a position to help to bridge the financing gap and industry's experience of addressing NCDs outside humanitarian settings can also be leveraged.

However, there remain concerns about conflicts of interest, particularly with the pharmaceutical industry. Two cases need to be made: first to the private sector to encourage its involvement in NCDs and secondly to other sectors that partnership can be of benefit. Transparency, accountability and honest discussions are essential, with a commitment by the private sector to engage in sustainable initiatives rather than short-term pilots.

An important barrier to partnerships is the absence of a clear set of guidelines or priorities around which to coalesce. WHO has already developed a set of 'best buys' for NCDs – so the development of a set of 'best buys' specifically for NCDs in humanitarian settings would indicate to potential partners that there is a costeffective business case for action. The best buys would ensure a more coordinated approach, responding to actual need rather than to the ideas of individual partners.

#### Discussion

Developing new best buys will not be easy, particularly given the paucity of evidence around NCDs in humanitarian settings – but developing a tailored set of existing best buys would be 'really something' and 'realistic and possible!' (Bente Mikkelsen, WHO).

Partnership will be essential, including involving civil society as an integral part of the solution, as well as driving advocacy. But there will be a challenge around the lack of a common language between the NCD actors and the humanitarian, donor and private sectors. Misunderstandings could extend to the term 'best buys'. An alternative form of words – such as 'priority cost-effective interventions' – might be more appealing. Positive engagement with the private sector is a matter of 'knowing who to speak to and where to push' (Lene Aggernæs, MFA) – for example, engaging with individual CEOs of relevant companies. Another way to leverage consistent funding would be the creation of a 'global fund' to pool finances and resources to address NCDs in humanitarian settings. The Grand Bargain, a platform for humanitarian funding, bringing together more than 30 of the world's biggest donors and aid providers, could also be an important stakeholder.

NCDs should be included in every health-related response in humanitarian settings, making existing funding go further and catalysing new partnerships. Integrated care takes advantage of synergies between different initiatives – for example, if a funder is interested in maternal health, diabetes checks could be included in the package of care – and is therefore more sustainable.

*"Involvement of the private sector is essential - but it is difficult"* 

- Bootcamp participant

#### How? Campaign ideas

A powerful campaign video was produced at the Bootcamp targeting WHO and very specifically the former mayor of New York Michael Bloomberg, the WHO global ambassador in NCDs acknowledging that he is also an important donor.

In this short video, a health worker from Syria address the WHO ambassador directly expressing deep frustration and upset by lived experience of people in humanitarian crises dying of preventable NCDs complications and giving facts and figures to the problem.

It urges him to mobilise resources and acknowledges the need to use financial and human resources in the most fiscally responsible way leveraging all partners – public and private sectors, academia, NGOs and local communities themselves.

Finally, the video encourages the involvement of a specific stakeholder who is well placed to initiate the best-buy process by undertaking an analysis of cost-effectiveness of what works in humanitarian settings.

The main campaign message highlights that to ignore NCDs in humanitarian settings is to compound the difficulties facing some of the world's most vulnerable populations: 'Invest in NCDs: leave no one behind!'

### **Common threads**

The many common threads across the discussions underline the point that action on NCDs in humanitarian settings should be addressed holistically. The Bootcamp was clear that NCDs are under-recognised and underfunded in humanitarian emergencies. Interventions – where they exist at all – are fragmented and siloed, leaving people living with NCDs unable to manage their own care. Building political will, activating new funding sources and making the case for urgent action are urgently required.

#### Working together

- The funding and action gap can only be bridged through cross-sector collaboration that brings together the complementary strengths of different stakeholders. Partnerships, bringing together the humanitarian, development and health sectors are essential.
- Challenges in making partnership work due to distrust, private sector conflicts of interest and different priorities needs to be overcome by open and honest dialogue. Civil society and young people should play a key role in pushing for change and driving the necessary political will and donor funding.

#### Making a stronger case

- There is a need for more data, evidence and analysis; to encourage better data-gathering using a variety of methods, to guide consistent protocols, to underpin a personal datamanagement system, to provide the rationale for prioritisation, and to build the case for funding.
- Advocacy is particularly challenging because NCDs are *'not relevant and "sexy" for the media'*: there is a need to build a strong narrative around the need for action.
- Share what works from the field whether case studies, personal stories, or peer-to-peer learning.

*"Involve the community in designing health promotion – we can't make them stop smoking just because we say so!"* 

– Bootcamp participant



## Community based and people-centred approach

- Local communities where we live, learn, work and play – are the first line of defence against NCDs. Co-creation with people who will be delivering and benefiting from programmes is essential if initiatives are to be feasible, practical, and culturally acceptable.
- Health-care must take a people-centred approach, addressing the needs and concerns of people, building on their personal knowledge and capacity to turn them into agents of their own health.
- Capacity, skills and knowledge are all to be built locally – including health and community workers. This is a more sustainable approach – and patients are more likely to trust people from within their own communities.

*"Everyone is trying to create their own systems – and they don't work together!"* 

– Bootcamp participant

#### Integrating NCDs

- There are strong co-morbidities between different diseases and between physical and psychosocial/mental health, particularly under the extreme stress of living in an emergency setting, which require a holistic approach to health.
- NCD care must be better integrated into existing humanitarian responses, guidelines and protocols.
- Careful thought must be given to what 'care' should cover – i.e. 'when should you start and when should you stop in a humanitarian setting?' Should prevention be part of outpatient care, or is this beyond what is possible in a crisis? Is screening ethical in a situation in which little or no treatment would then be available?

*"Mental health is an NCD in itself but is also a risk factor that prevents interventions from being successful"* 

- Bootcamp participant

#### Short-term versus long-term

- There are no short-term solutions for chronic health conditions, and there is an inevitable tension between the acute, humanitarian phase and the longer-term approach needed for the recovery/development phase.
- Multi-year funding from governments and donors is urgently needed, addressing preemergency planning, during the crisis itself, and the longer-term response.
- The prevention of NCDs needs to be taken seriously, because a long-term approach builds resilience prior to an emergency and hastens recovery after it.
- And finally, while there is a need for pragmatism about what can be achieved in the short term, do not let this put off action today!

"We need creative ways to encourage healthy behaviour in such a stressful context – this is the biggest challenge"

- Bootcamp participant

### **Final word**

#### The impact of advocacy

In early July, a few days after the Bootcamp, an Interactive Hearing was held at the United Nations – an opportunity for civil-society organisations to raise their priorities in NCDs internationally, ahead of the High-Level Meeting on NCDs in September 2018. At the Bootcamp, participants asked how they could best influence this process and bring NCDs in humanitarian crises into the discussions – so the Bootcamp partners produced a Call to Action. This set out the urgency of NCDs in humanitarian crises, and Bootcamp participants were asked to share it with their own organisations and with those attending the Interactive Hearing.

At the hearing, four organisations called for NCDs in humanitarian settings to be prioritised, including a strong statement from the International Federation of the Red Cross and Red Crescent Societies, taking inspiration from the Bootcamp.

Civil society must come together in a clear call to extend the focus on NCDs to include humanitarian settings. 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.

A new Political Declaration, to be adopted by heads of state and government at the 2018 United Nations General Assembly Third Highlevel Meeting on the prevention and control of NCDs, would be a significant step forward. By explicitly calling for action on NCDs in humanitarian settings it would address a priority that had been omitted from the two previous Declarations (in 2011 and 2014). The 2018 United Nations High Commissioner for Refugees (UNHCR) Global Compact on Refugees also incorporates specific mention of the need to address chronic diseases, including access to treatment to prevention, showing an increasing recognition of the need to address this gap.

Now is the time to take this document and the policy asks within it, and use them to build on the Political Declaration, to inform your advocacy with governments and donors, to provide inspiration for research, and to seek ways to take forward effective partnerships.

"I'm looking forward to seeing how the Bootcamp ideas will be developed in the weeks, months and years to come!"

<sup>-</sup> Bootcamp participant

#### Want to know more?

There is a package of further information available online on the Danish Red Cross website at https://www.rodekors.dk/ncd-bootcamp.

#### Acknowledgements

The Bootcamp partners – the Danish Red Cross, NCDFREE, the University of Copenhagen and the International Federation of the Red Cross – would like to thank:

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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.







