Essential medicines and basic health technologies for noncommunicable diseases: towards a set of actions to improve equitable access in member states

WHO Discussion Paper
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CLAN (Caring & Living As Neighbours) is an Australian-based, globally focused NGO dedicated to the vision that all children living with Non-Communicable Diseases (NCDs) and other chronic health conditions in resource poor communities around the world enjoy a similar quality of life to that of their wealthier neighbours.

Since 2004, CLAN has pioneered a rights-based, community development approach that places children, their families and carers at the heart of the solution, bringing local and global communities together to support each other. In 2011 CLAN founded NCD Child (www.ncdchild.org) as an independent global coalition with the vision of integrating children and adolescents within the international NCD, health and development discourse.

CLAN's framework for action is built around five pillars of action:
1. Affordable access to medicines and equipment
2. Education, research and advocacy
3. Optimal medical management
4. Strong family support groups
5. Promoting financial independence

CLAN offers the following responses to the WHO discussion paper with respect.
**Question 1**

What lessons can be learned from access programmes for the Millennium Development Goals that are relevant for access to essential medicines and basic health technologies for NCDs, at the global, regional and country levels?

**Lesson 1: the vital importance of a committed life-course focus that specifically considers people of ALL ages in ALL policies and actions relating to access to medicines.**

Children and adolescents are at especial risk of neglect. Where specific efforts are NOT made to include children and adolescents in policies and programs, they risk being systematically excluded: inadequate access to paediatric doses of HIV medications and paediatric palliative care are relevant historic examples for member states to reflect upon.

Conversely, where children and a life-course approach are a priority of essential medicines and basic technologies access schemes, the outcomes can be spectacular: the prevention of mother-to-child transmission of HIV is such an example.

Requested edits:

- Acknowledgement of NCDs as a cause of premature deaths in children (as per member states at the 2013 World Health Assembly) in the background information would be essential.

- Penicillin should certainly be included as an essential medicine for the prevention of Rheumatic Heart Disease (paragraph 6).
Are there specific examples of best practices and successful case studies on country-led initiatives to improve access to essential medicines and basic health technologies for NCDs? What were the critical success factors for these initiatives?

Lesson 2: Imperative of a person- and community-centred approach

CLAN (Caring & Living As Neighbours) adopts a community development approach to NCDs that identifies all people living with the same NCD as members of a united, non-geographically based community. Consultation and a health needs assessment of those living with CAH (Congenital Adrenal Hyperplasia) in Vietnam in 2005 by CLAN identified challenges with access to life-saving medicines as the greatest burden for families. In response to this community health needs assessment, CLAN undertook to facilitate short-term humanitarian donations of essential medicines (to keep CAH community members alive) whilst longer-term solutions were identified and worked towards.

In 2008 the implementation of the CAH RAPIA (an adaptation of the International Insulin Foundation (IIF) Rapid Assessment Protocol for Insulin Access (RAPIA) to review access barriers relating to hydrocortisone and fludrocortisone tablets for people living with Congenital Adrenal Hyperplasia) was successfully undertaken in Vietnam. This was a collaborative effort by CLAN, the IIF, local health professionals and representatives of the Vietnamese Ministry of Health and other national entities. A key recommendation of the CAH RAPIA identified as a goal the inclusion of hydrocortisone and fludrocortisone tablets within the World Health Organisation Essential Medicines List for Children (WHO EMLc). This action was undertaken and shortly thereafter the medicines were registered in Vietnam by the government and included in the national insurance scheme.

The impact of improving local availability and affordability of these two essential medicines for the community of people living with CAH in Vietnam has been extremely positive. Mortality has reduced dramatically, awareness of CAH has increased and the national prevalence has increased more than ten-fold in the last decade.

Critical success factors included: a community development approach consulting members of the CAH community on their challenges and burdens; urgent humanitarian donations of essential medicines so that people did not die whilst longer term solutions were found; collaborative efforts to clearly identify root causes and barriers to access issues (using the RAPIA); inclusion of drugs on the WHO EMLc; efforts nationally to register the drugs and make them available on the national insurance scheme to promote affordable access to all.
Question 2
Are there other bottlenecks limiting access to essential medicines and basic health technologies for NCDs not mentioned above that need to be addressed?

Which bottlenecks would you consider the three most important to be tackled?

Bottlenecks relating to rational selection and use:

1. NCD Community empowerment
NCDs are chronic conditions. The health sector must move beyond outdated notions of “delivering” health care to patients who frustrate through “lack of adherence”. Instead, the focus on a person- and community-centred empowerment approach is required. To this end, the 2015 WHO papers on a global strategy on people-centred and integrated health services are excellent and should inform this paper on access to medicines and technology for NCDs more fully. Education and community connections reduce stigma and shame and build capacity to improve adherence.

Bottlenecks relating to reliable health and supply systems

2. Failure of health and supply systems to ensure a life-course approach
The need for a focus on human rights law is addressed in paragraph 17, but greater emphasis is required on the obligations of member states and others to protect and promote the rights of humans to life and health through affordable access to essential medicines.

In particular, special mention on the rights of children should be included. Unless specific enquiries are made by member states into the key challenges and burdens facing children who are living with NCDs in their own country, the needs of the most vulnerable will be overlooked.

A perceived lack of need does not equate to an actual lack of need. Children suffer, children die and for the most part, parents deal with their grief by moving on and trying to forget what has happened. In this way voices are not heard. Stories will remain lost unless efforts are made to hear them.

With inaccurate systems in place to record deaths of children accurately, the vicious cycle of suffering and silence will continue unabated. Member states must make specific efforts to consult with leading paediatricians in their countries to learn more about the children who suffer most from NCDs, and the
medicines they most need access to if the children are to achieve their rights to health and life.

3. **WHO EML and EMLc as resources for NCD communities**

As noted in paragraph 12, not all drugs included in the WHO EML and EMLc, are affordably available to people living with NCDs in all countries. These seminal resources must be a focus of collaborative, co-ordinated global efforts. At a minimum, future efforts should focus on ensuring all drugs on the WHO EML and EMLc are affordably available in every country.

Health professionals at the coal face can frequently identify urgent priorities in terms of access to medicines to prevent human suffering. However the overly complex regulatory and legislative processes they need to negotiate to drive change can overwhelm even the most dedicated and caring professionals. Greater support and clarity is needed to empower health professionals to negotiate this terrain. The WHO lists should provide more guidance and empower health professionals and NCD communities more effectively in this regard.
Question 3
How best can governments utilize multistakeholder collaboration, including the private sector, to increase country capacity to improve access to medicines and other health technologies for NCDs within health systems?

What additional information do donors and countries need in order to understand the business case for funding medicines and other health technologies for NCDs?

For over a decade, CLAN has been modelling multistakeholder collaboration whilst also maintaining the communities of people living with NCDs as the visual hub of all action:

- engagement with the private sector has been a vital part of our successful efforts to improve quality of life for those affected. For example, donations of hydrocortisone tablets by Alphapharm Pty Ltd Australia as a short-term humanitarian measure to keep members of national CAH Communities alive whilst longer-term solutions to local registration are sought have been invaluable

- involvement of local health professionals has enabled cost-effective and rapid means of consult with NCD Communities nationally to identify local priorities. Those living with NCDs – and their families – can be rapidly identified through existing health systems, and data collated relating to their needs and priorities. Educational support and training for health professionals has strengthened their resolve to strive for equity for their patients.

- involvement of fellow NGOs has enabled NCD Communities to connect internationally with like-minded organizations and limited the need to reinvent the wheel

- leadership by ministry of health and government departments has been vital to fast-tracking regulatory and legislative changes that have improved access to medicines

- translation of educational resources into local languages has helped families understand the importance of taking medicine and adhering to treatment schedules

- involvement of NCD community members has provided sustainable continuity and purpose. Empowerment of community members has helped fast-track local action.
Moving forward governments might consider:

- stronger involvement of health economists to clearly demonstrate the cost benefits to governments of improving access to medicines and technologies will be vitally important. For instance, newborn screening is adopted religiously by all high income countries, yet low and middle-income countries lag behind. Health economists are needed to drive home the benefits of investing in health in new ways.

- investing directly in their national NCD Communities, supporting grassroots activities by those most affected by - and most passionate about - NCDs to improve quality of life for their fellow citizens. Support with capacity building (to facilitate implementation, evaluation and monitoring of activities) would be important.

**Question 4**
Do Member States perceive a need for the development of a bottleneck assessment tool on NCDs?

What assessment tools are countries and partners already using that could be adapted for assessing bottlenecks for NCDs?

The processes and tools outlined in p24 are important and encouraging.

In particular, CLAN reports exceptional success using the RAPIA tool that was developed for diabetes and adjusting it for another NCD (Congenital Adrenal Hyperplasia) and implementing it in Vietnam.

We recommend member states take a systematic and life-course focused approach to identifying and assessing bottlenecks. In particular, consider the needs of children living with NCDs and not just the perspective of adults living with NCDs.
Question 5
What are the most pressing needs for Member States as regard the availability of standard guidelines for management of the major NCDs and rational use of medicines for the alleviation of pain during palliative care?

How can Member States strengthen implementation of existing WHO guidelines for management of NCDs at the first level of health care?

What are the outstanding needs to improve patient acceptability of and adherence to medicines and other technologies for NCDs?

The empowerment of NCD Communities must be an urgent priority. Akin to the disability movement, the consideration should be “Nothing about us without us”.

Meeting with those living with NCDs, consulting with health professionals who support them and better understanding the challenges and burdens facing NCD Communities will help member states prioritise future action.

Again, the WHO’s recent papers on person-centred health care are strongly applauded.

Question 6
What constraints do Member States face in accessing accurate and transparent information about procurement prices and quality of essential medicines and other health technologies for NCDs?

How useful do stakeholders consider an initiative on knowledge sharing to be?

If the outcome is to improve quality of life for those living with NCDs, then again, consultation and collaboration with NCD Communities will help identify priorities and knowledge gaps. After speaking with those most affected, member states will soon have an appreciation for where more accurate and transparent information is required.

Knowledge sharing internationally (especially by supporting NCD Communities to connect internationally) is almost universally beneficial, and is particularly valid given multi-national pharmaceutical industries now operate globally.
Question 7
Are there any gaps in current tools available to Member States that need to be addressed to adequately capture the quantification of needs for essential medicines and basic health technologies for NCDs?

How best can Member States build and sustain capacity for effective national surveillance and data collection to forecast needs for medicines and other health technologies for NCDs?

The reality is that in LMICs, the data collection and information systems alluded to are not yet operational. They are still a long way off in many cases.

Should we do nothing in the interim?

No of course not.

What can be done?

It is simple, cost-effective and efficient to communicate directly with those most affected and learn from them and their health professionals what needs to be done. Operating with a range of stakeholders from multiple sectors to drive the changes identified by the communities is key to success. CLAN has been demonstrating over the last decade that population-wide changes can be driven at low-cost and high-speed when NCD Communities are engaged, consulted and empowered to collaborate with a broad range of partners.

Development of patient registers that contribute to community development (and not just number crunching) would be an important first step.
Question 8
How best can Member States ensure the availability of safe, effective and quality-assured medicines and other health technologies for NCDs?

How can Member States strengthen quality assurance capacity for insulin, asthma inhalers and other more complex NCD essential medicines and health technologies?

As noted in response to question 2, not all drugs included in the WHO EML and EMLc, are affordably available to people living with NCDs in all countries. The WHO EML and EMLc are seminal resources and must be a focus of collaborative, co-ordinated global efforts. The WHO would be well served to consider ways these tools – and others, such as the WHO hospital handbook – could help build capacity of member states to drive change in this space.

Question 9
What are the best ways to increase awareness of the importance of essential medicines and basic health technologies to prevent and control NCDs?

What other measures can be taken to enhance advocacy efforts to improve access to essential medicines and basic health technologies for NCDs in countries?

Strengthening and investing in NCD communities should be a core priority.

Empowering those living with NCDs to share their stories, engage media and national non-government organizations and philanthropists would be powerful. Reflecting on the achievements of the HIV movement in this regard would be appropriate.
Question 10
What key knowledge gaps are present for NCDs and how can these gaps be bridged using research?

Research that addresses the priorities of the NCD Communities would be most appropriate.

Given the importance of preventing NCDs for long-term sustainability, research that addresses life-course issues (as led by the DOHaD movement) would seem the most urgent priority. In this regard, research that addresses families has the benefit of impacting across generations rather than limiting itself to an individual focus.

In this regard, stretching our understanding of “person-centred care” to “family- and community-centred care” perhaps offers advantages that have not yet been fully explored.

References: