

Opinion

Neglected Tropical Diseases and Mental Health: Progress, Partnerships, and Integration

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Neglected tropical diseases (NTDs) are increasingly recognised as major drivers of psychosocial morbidity in affected individuals and their caregivers. Nevertheless, there has remained a lack of prioritisation at the policy level of some of the most stigmatising and chronic NTDs, with subsequent under-representation within NTD programmes. In response, the Neglected Tropical Disease/Non-Governmental Organization/Network (NNN) has established a Mental Wellbeing and Stigma Task Group (MWS) to address these issues through a comprehensive research agenda. In our article, we highlight the progress in understanding the scope of the mental health impact of NTDs and the innovative practice emerging in this area. Finally, we examine opportunities for integration of mental and physical health for individuals with NTDs.

NTDs and Mental Health: A Growing Evidence Base

The scale of psychological comorbidity in the one billion affected worldwide with **neglected tropical diseases (NTDs)** (see [Glossary](#)) has become increasingly recognised by the NTD community after being highlighted in 2012 [1]. As of October 2018, over 3000 studies have been added to an online repository for cross-cutting NTDs research – **InfoNTD** – a significant proportion of which are related to the psychosocial impact of NTDs¹. In this time, along with an increased depth of research for a number of well-studied NTDs, i.e., leprosy, lymphatic filariasis (LF), and cutaneous leishmaniasis (CL), there has also been a large growth in the evidence base for a growing number of lesser studied NTDs (Table 1). Per InfoNTD, a holistic study (quality of life, stigma, psychological distress, or physical disability) now exists for the large majority of NTDs (17/23), including studies of eight additional NTDs since 2012–Buruli ulcer (BU) [2], Chagas' disease [3], chikungunya [4], mycetoma [5], podoconiosis [6], schistosomiasis [7], soil-transmitted helminths (STH) [7], and visceral leishmaniasis (VL) [8]. Meanwhile, there has also been an increase in the number of studies quantifying the prevalence of common mental health conditions (**anxiety** and **depressive disorders**) associated with NTDs, including studies of three additional NTDs since 2012–BU [9], LF [10], and podoconiosis [11].

Overall, control studies have consistently shown a significantly increased rate of depressive disorders in populations affected by NTDs, including patients [11–15] and caregivers [16–18], as well as affected communities [19]. For NTDs with a predominantly acute course, psychological comorbidity may normalise with full resolution of both primary symptoms [4,20–22] and secondary symptoms (including pain, fatigue, and itch) [23,24]. This effect is likely due to the positive psychological impact of physical and surgical treatment [25–29]. However, a key finding is that the psychological impact of NTDs is not restricted to active infection but extends

Highlights

The past 6 years has seen mental health emerge as a key cross-cutting area of NTDs research.

In this time, there has been a large increase in the number of holistic and psychological studies in NTD populations, adding to the evidence base of well-studied as well as lesser-studied NTDs.

In particular, chronic NTDs have emerged as an important risk factor for common mental health conditions, with prevalence rates of depression higher than those found in other common chronic diseases.

Nevertheless, there remains a significant lack of psychological intervention studies as well as large opportunities to translate this knowledge into integrated mental and physical care for affected individuals.

Partners in the Mental Wellbeing and Stigma (MWS) task group of the NTD/NGO/Network (NNN) are working to address many of these areas through a comprehensive research agenda in collaboration with the World Health Organization and other key partners.

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Table 1. Evidence Base for Mental Health and NTDs. Selected Holistic, Psychological, and Intervention Studies (as per InfoNTD, Medline, and Other Online Sources, October 2018)

NTD	Holistic (QoL; stigma; physical disability)	Psychological (Anxiety; depression)	Holistic/psychological intervention
Buruli ulcer	Ackumey M.M. <i>et al.</i> (2012) [2]; Klis S. <i>et al.</i> (2014) [21]	Kpadonou T.G. <i>et al.</i> (2013) [9]	Amoussouhoui A.S. <i>et al.</i> (2016) [44]
Chagas' disease	van't Noordende A.T. <i>et al.</i> (2016) [3]; Sousa G.R. <i>et al.</i> (2018) [62]	Ozaki Y <i>et al.</i> (2011) [63]	–
Chikungunya	Soumahoro M.-K. <i>et al.</i> (2010) [23]; Courturier E. <i>et al.</i> (2012) [4]	–	–
Cutaneous and mucocutaneous leishmaniasis	Reithinger R. <i>et al.</i> (2005) [64]; Vares, B. <i>et al.</i> (2013) [65]; Al-Kamel M.A. (2017) [66]	Yanik M. <i>et al.</i> (2004) [12]; Simsek Z. <i>et al.</i> (2005) [14]; Torkashvand F. <i>et al.</i> (2016) [30]	Nilforoushzadeh M.A. <i>et al.</i> (2010) [38]
Dengue	Lum L.C. <i>et al.</i> (2008) [67]	Bhatia M.S. <i>et al.</i> (2017) [22]; Gunathilaka N. <i>et al.</i> (2018) [31]	–
Echinococcosis	Torgerson P.R. <i>et al.</i> (2001) [68]	–	–
Foodborne trematodiasis	–	–	–
Guinea-worm disease	–	–	–
Human African trypanosomiasis	–	–	–
Leprosy	Tsutsumi A. <i>et al.</i> (2007) [13]; van Brakel W.H. <i>et al.</i> (2012) [69]; van't Noordende A.T. <i>et al.</i> (2016) [3]	Tsutsumi A. <i>et al.</i> (2007) [13]	Floyd-Richards M. <i>et al.</i> (2000) [39]; Sermittirong S. <i>et al.</i> (2014) [42]; Peters R.M.H. <i>et al.</i> (2015) [46]; Lusli M. <i>et al.</i> (2016) [47]
Lymphatic filariasis	Perera M. <i>et al.</i> (2007) [70]; Abdulmalik J. <i>et al.</i> (2018) [71]	Obindo J. <i>et al.</i> (2017) [10]	–
Mycetoma	Bakhiet S.M. <i>et al.</i> (2018) [5]	–	Bakhiet S.M. <i>et al.</i> (2018) [5]
Onchocerciasis	Hagan M. (1998) [72]; Okoye I.C. <i>et al.</i> (2007) [73]; Mbanefo E.C. <i>et al.</i> (2010) [74]	–	–
Podoconiosis	Mousley E. <i>et al.</i> (2013) [6]	Bartlett J. <i>et al.</i> (2016) [11]	–
Rabies	–	–	–
Scabies	Jin-gang A. <i>et al.</i> (2010) [20]	–	–
Schistosomiasis	van't Noordende A.T. <i>et al.</i> (2016) [3]; Fürst T. <i>et al.</i> (2012) [7]	–	–
Snake bite	Williams S.S. <i>et al.</i> (2011) [15]	Williams S.S. <i>et al.</i> (2011) [15]	Wijesinghe C.A. <i>et al.</i> (2015) [40]
Soil-transmitted helminths	Fürst T. <i>et al.</i> (2012) [7]	–	–
Taeniasis	–	–	–

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Table 1. (continued)

NTD	Holistic (QoL; stigma; physical disability)	Psychological (Anxiety; depression)	Holistic/psychological intervention
Trachoma	Dhaliwal U. <i>et al.</i> (2006) [25]; Habtamu E. <i>et al.</i> (2015) [24] Habtamu E. <i>et al.</i> (2016) [28]	–	–
Visceral leishmaniasis and Post-kala-azar dermal leishmaniasis	van't Noordende A.T. <i>et al.</i> (2016) [3]; Pal B. <i>et al.</i> (2017) [8]	–	–
Yaws	–	–	–

to those NTDs with chronic sequelae [9,12,15,30,31]. This is important for two reasons: (i) many NTDs are chronic conditions that extend well beyond the active infection [1]; (ii) systematic reviews of several stigmatising chronic NTDs (CL [32], leprosy [33], and LF [34]) show that chronic NTDs are associated with higher rates of common mental health conditions than other common chronic diseases [35]. Because the psychosocial impact of chronic NTDs is lasting, it therefore follows that physical intervention alone is insufficient to address these larger holistic aspects of disease on the lives of affected individuals and their caregivers.

Nevertheless, given the primary focus of NTD policy on disease elimination, it is unsurprising that chronic NTDs and their associated psychological impact has only recently been recognised [36]. For example, most chronic NTDs (e.g., leprosy, CL, and BU) have among the lowest **disability burdens** as estimated by **Global Burden of Disease (GBD) Studies** [37], which is due to the under-representation of chronic sequelae and their impact in both prevalence and disability estimates. Similarly, integrated chronic and psychological care is not a focus of NTD programmes at present. This is also partly due to the fact that, despite recent progress in this space, there remains a significant lack of psychological interventions in the NTD literature. To date, psychological intervention studies have been conducted in just three NTDs (CL [38], leprosy [39], and snake bite [40]), with social intervention studies having been assessed for a further three NTDs (BU [41], leprosy [42], and mycetoma [5]). Equally, there have been no intervention studies targeting chronic NTD sequelae, representing a clear area for future work.

The NTD NGO Network (NNN): Progress in Partnership Development

The network representing civil society organisations working in NTDs (**NNN**) has expanded in membership, influence, and scope significantly over recent years. The cross-cutting task force addressing issues of disease management, disability, and inclusion (DMDI) has established a task group, the Mental Wellbeing and Stigma (MWS), to focus on NTD-related stigma and the mental wellbeing of those affected by NTDs alongside their physical needsⁱⁱ. The aims of the group are: (i) to support and develop resources for advocacy of affected individuals and to promote their empowerment; (ii) to ensure NTD programmes include interventions which promote positive attitudes and behaviour of communities to those affected and address structural discrimination; (iii) to promote self-advocacy and expression of the needs of those affected; and (iv) to increase the awareness of the rights and responsibilities of those affected and those who provide services to them, including their caregivers. At a recent DMDI meeting, a person affected by LF described his experiences and priorities (Box 1).

Glossary

Anxiety disorder: the second most prevalent group of mental disorders; characterised by feelings of anxiety and fear; the extended duration of symptoms makes anxiety disorders more chronic than episodic disorders. The most prevalent anxiety disorder is generalised anxiety disorder (GAD), commonly termed 'anxiety'; however, anxiety disorders also include phobia disorders and obsessive-compulsive disorder (OCD).

Coalition for Operational

Research on NTDs (COR-NTD):

an international group of researchers, program managers, and in-country partners, with a shared goal of optimising NTD control and elimination.

Depressive disorders: the most prevalent group of mental disorders; characterised by sadness, loss of pleasure, guilt, low self-worth, disturbed sleep or appetite, fatigue, and poor concentration. Made up of major depressive disorder (an often relapsing and remitting condition of varying intensity, commonly termed 'depression'), and dysthymia (a more persistent condition of lower intensity than MDD).

Disability burden: a concept to describe the impact of a condition on the affected population, and comprised of a disability (YLD) and a mortality (YLL) component. Estimates of disability burden are used to compare and rank the impact of different conditions.

Global Burden of Disease (GBD)

Study: GBD studies aim to rank conditions/diseases according to their disease burden, using the disability-adjusted life year (DALY) metric. Formerly these studies were conducted by WHO, though GBD studies are now carried out at regular intervals by the Institute of Health Metrics and Evaluation at the University of Washington.

Global mental health: a growing international movement aimed at improving recognition of mental illness as well as strengthening mental healthcare provision for affected individuals worldwide.

InfoNTD: an online platform and repository for cross-cutting research, tools, and other information on neglected tropical diseases, including

Box 1. The Experience of a Person Affected by a Neglected Tropical Disease**The Experience of Muhammad Jidda, Nigeria**

Mr Muhammad Jidda was born in Borno State in 1959 in northern Nigeria to a family of nomadic cattle keepers – a member of the Shuwa Arab tribe. He started school in Maiduguri before moving to Kano for post-primary schooling. After graduating in Public Administration and Rural and Community Development (postgraduate diploma), he joined the Nigeria Customs Service, rising through the ranks until he reached the senior rank of Superintendent of Customs.

In 1990, he went to see a doctor in Port Harcourt as he had a swelling of his buttocks, and was diagnosed as having tuberculosis (TB) and given a long course of antibiotics. This was ineffective, and he noted that his right leg was also swelling. This was eventually diagnosed as lymphatic filariasis by visiting international doctors working with Doctors Without Borders. After being diagnosed, he was told that there was nothing that could be done for him as there was no effective treatment available.

His leg continued to swell – a process commonly called elephantiasis. Many of his friends told him that this was a spiritual problem, and that medicine could not help him. People thought that he was cursed by someone who was not happy with him because of his job as a customs officer. Despite seeking treatment from both traditional healers ('babalao') and Islamic healers, he saw no benefit, and it was a very expensive process.

When his leg became very large, he travelled long distances to specialist hospitals and was given repeated skin-graft surgery to reduce the size of the swelling. Mr Jidda estimates that he spent more money traveling to Abuja, the capital of Nigeria, trying to get help, than he gained for his efforts.

The situation made him feel hopeless, and he felt very low, not finding any reason to live, and he gradually withdrew from the world. He rarely left the house, because when he went out, people would run away from him. People did not want to be near him, fearing infection. He has been married five times, and on four occasions his wives left him because of his disability. His wife now is supportive, and they have two children. He never spoke to anyone about his low mood and hopelessness, and he did not consider seeking psychiatric help, as this would label him as 'mad', something that was even worse than the situation he was already in.

Although the disease caused occasional periods of fever, and he found difficulty walking, he was still able to carry out his work. Despite this, the Customs Service decided that he should retire early, a decision that he did not agree with. This has had a severe impact on his ability to have a sustainable income. In addition, the treatment that he must pay for costs more than his small pension, and he is now reliant on friends and family.

Mr Jidda was invited to participate in a process of identifying research priorities, and shared what he considered to be the changes that would make the most difference to his life, and to promoting better outcomes for others affected by NTDs.

Key Messages

- The delays in getting help due to lack of good local medical expertise and care caused undue suffering and expense. Obtaining good treatment and support is still a major challenge. Better and early access to medical treatment is essential, thereby reducing the potential for inappropriate expenditures which may be catastrophic to a family.
- There are still many people with conditions who do not seek medical help. This is partly due to lack of local services, partly due to their belief that these are spiritual problems, and their fear of diagnosis and the resulting stigma. There is a need to raise awareness. Affected people are well placed to take these messages to communities around them.
- There is frequently no available support for emotional distress throughout this period of disability. Emotional support should be accessible for affected individuals, but needs to be offered in a nonstigmatising way and not associated with the 'psychiatry or mental illness' label, otherwise people will be reluctant to use it.
- Difficulty with employment and high costs of managing the physical effects of NTDs make finding sufficient money to support a family very challenging. Support for livelihood development should be considered for people with disabilities as part of comprehensive programmes.

disability, inclusion, stigma, and psychological comorbidity.

Mental Health Innovation

Network (MHIN): an online network for the global mental health community to share knowledge and resources in order to improve the quality and coverage of mental healthcare.

Neglected tropical diseases

(NTDs): a diverse group of ~20 communicable diseases recognised by WHO as being underfunded relative to other conditions of equal prevalence; NTDs affect predominantly the world's poorest populations, and many have a chronic course, are physically disabling, and/or are associated with stigmatisation.

NNN: the Neglected Tropical Disease (NTD) Non-Governmental Organization (NGO) Network. A global platform for NGOs to work together to tackle important issues in NTD control and development. A cross-cutting task force on Disease Management Disability and Inclusion (DMDI) has recently developed a mental health research agenda through its Mental Wellbeing and Stigma (MWS) task group.

Noncommunicable diseases

(NCDs): noninfectious diseases characterised by a chronic and slowly progressive course. Common examples include cardiovascular diseases, cancers, chronic respiratory diseases, and diabetes. In recent years mental health disorders have been more clearly defined within the NCD category, sharing many characteristics and potential common treatment platforms as other NCDs.

Critical to these aims is the need to engage in a structured programme of research to further clarify key conceptual questions and explore practical implementation issues. This will require resources for field studies to demonstrate proof of concept that interventions can reduce the burden of mental health and stigma associated with NTDs. Increasing awareness of the stigma and mental health dimensions of NTDs with organisations and programmes involved in NTD work is essential to this goal, as well as developing and sharing resources for advocacy and

evidence-based interventions. A major achievement of the MWS task force to date has been to engage the World Health Organization (WHO) Department of Mental Health and Substance Abuse in developing a joint mental health intervention manual for NTDs, which is due to be published in 2019.

Integration of Mental and Physical Health for NTDs

The **noncommunicable diseases (NCDs)** community has recently emphasised the benefits of integrating mental and physical healthcare services for individuals living with chronic conditions [43]. Similarly, individuals with chronic NTDs have emphasised the inclusion of psychological care as a key to improving patient care [44]. It is therefore important to consider how integration of mental healthcare might be incorporated into health systems for individuals with NTDs. Several general and specific considerations for integration are highlighted below, combining recent innovation in mental health and NTDs with recommendations for integration from the NCD community, and recent advances in **global mental health**.

General Considerations

A range of existing integration strategies are applicable to all NTDs, each of which are dependent upon the capacity of a given country. As the majority of individuals affected by NTDs are found in low-resource settings, these would practically involve integration of mental health into either NTD programmes, primary care, or community-based activities; a stepped care approach has been shown to be effective [43], with increasing resources afforded to those at the highest risk of significant psychological impact. Indeed, for individuals with acute NTDs in low-resource settings, it may be most appropriate to continue to focus on physical intervention given the positive psychological benefits of physical treatment discussed above and the tendency for improvement in psychological comorbidity with full clinical recovery. In such settings, it may be more suitable to focus resources instead on NTDs with chronic sequelae and/or high levels of stigmatisation.

Given the challenges of specialist mental health service provision [45], a further important consideration is the need for culturally sensitive psychological measurement tools that are practical for large-scale and nonexpert administration. The recent development of a holistic tool kit for NTDs is promising and has been validated in different NTD populations [3], but its use relies upon time and expertise that is currently not available in the many settings where NTDs are most prevalent. Nevertheless, research into leprosy has demonstrated the effectiveness of several stigma and group counselling interventions suitable for administration by nonspecialists [46,47], supporting similar research findings in the global mental health community [48].

Importantly, a grass roots approach can be an effective way of providing continuity of care for individuals affected by chronic NTDs. A good example of this approach is the BasicNeeds approach, centred upon peer support and economic empowerment groups for current and former mental health service users [49,50]. This community-led approach has provided advocacy and empowerment to affected individuals and should be further explored for those affected by NTDs. Elsewhere, the mass uptake of social media allows that community-led solutions need not be geographically restricted. For example, the recent use of a social media app has helped connect and empower Brazilian families affected by congenital Zika syndrome, leading to the development of a successful grass roots NGO [51].

Specific Considerations for Preventive Chemotherapy NTDs (PC-NTDs)

NTD programmes are varied in their approach to the control and elimination of specific NTDs, however some programmes have a common basic infrastructure that could be

adapted for integration of psychological and physical care. For example, mass drug administration (MDA) programmes are specialised NTD programmes that deliver high quality, cost-effective prophylactic treatment to communities at risk of five PC-NTDs – LF, STH, schistosomiasis, onchocerciasis, and trachoma. Such programmes have a direct physical health benefit to at-risk communities for PC-NTDs, but have also been shown to confer a psychosocial benefit [26].

Following a recent pilot physical-disability study by the international NGO Sightsavers in Ghana using the Washington Group Short Set of Disability Questions, it is now being investigated whether the MDA programme could also be used as a platform to identify suspected new and chronic cases of LF and onchocerciasis with mental health problems through the use of nonspecialist trained health volunteers. The benefits to MDA programmes of such an integrated strategy would be to reinforce weaker aspects of the MDA process such as the registration of community members during which time psychological screening could take place, as well as to improve overall compliance [52] and therefore improve MDA coverage. As the MDA programme targets at-risk populations at the prediagnostic level, this represents an interesting service delivery integration opportunity to address the larger socioeconomic impact of NTDs on affected communities [19].

Specific Considerations for Skin NTDs

NTDs with a predominant skin manifestation have recently been aligned in integrated control efforts [53,54], although the morbidity management component of these proposed activities has not explicitly included psychological assessment and care. This is significant because, among the NTDs, skin NTDs are the best-defined group for psychosocial impact. It is therefore important to determine how mental healthcare could be better included in this framework. The best example of a holistic approach to a group of skin NTDs is currently being tested for LF, podoconiosis, and leprosy – the EnDPoINT (Excellence in Disability Prevention Integrated across NTDs) programmeⁱⁱⁱ – and is based upon previous successful research for populations with podoconiosis in northern Ethiopia [11]. Differing from the MDA approach, the EnDPoINT approach is targeted to those with an existing diagnosis (acute and chronic) and is in this case delivered by specialists.

Considering the approach to individual skin NTDs, the international leprosy NGO, Lepira, has been successful in translating the findings of a large evidence base for leprosy stigma research [42] into its activities to date. Nevertheless, despite being the best studied NTD for psychological impact, there remain sizeable opportunities within national programs and international NGOs [55,56] to apply this research into integrated care for affected individuals. In the case of another well studied NTD, CL, these opportunities extend to refugee and displaced populations in the Middle East [57,58]. Interestingly, however, the holistic management of lesser studied skin NTDs, such as BU [41] and mycetoma [5], has found its way into local healthcare settings through a combination of specialist and community measures.

Concluding Remarks

Progress in research and partnership in the past 6 years has seen mental health emerge as a key cross-cutting area of NTD research. Currently, an increasing evidence base points to a disproportionately high prevalence of comorbid mental illness among individuals affected by NTDs, in particular, chronic NTDs. This finding illustrates the fact that, in order to eliminate NTDs ‘as public health problems’ [59], we must not only focus our efforts on the elimination of active NTD infection, but also tackle the residual impairment and associated psychosocial impact of chronic NTD sequelae. Given the unique stigma and socioeconomic impact of NTDs [60], as

Outstanding Questions

Identifying a research agenda for NTD-related stigma and mental health in order to better understand the issues, obtain baseline data, and then craft an evidence-based response. The results of a consultation at COR-NTD (November 2017):

What are the associations and comorbidities between individual NTDs and mental health outcomes?

What is the role of stigma on quality of life and mental health consequences?

What is the impact of NTDs and mental ill health on caregivers?

How can we best model the psychological impact of NTDs to better inform GBD estimates and generate economic burden figures?

What is the impact of physical treatment for NTDs on mental health outcomes?

What is the impact of mental health care on NTD outcomes?

How best can mental wellbeing activities be integrated into NTD care; identification, engagement, care packages, training, support and supervision; demand creation; holistic rehabilitation?

How to approach policy review and reform?

well as their links to poverty [61], individuals and communities affected by NTDs may well represent one of the highest risk populations for mental disorder. Importantly, these more neglected aspects of NTDs need to be championed first by the NTD community in order that more widespread recognition can occur.

As such, we have highlighted a growing number of effective psychosocial interventions which have been demonstrated in a number of NTD populations, and discussed future opportunities to scale up and practically integrate this growing evidence base into existing NTD programme activities. Success in this process is dependent upon the input of affected communities and those living with lasting sequelae of an NTD. Further engagement and knowledge sharing outside of the NTD community is also critical to drive future collaboration and innovation in this process. For example, the NTD community can gain valuable insights from the global mental health community in terms of community-led mental health assessment and delivery of care. Equally, the scale of mental health and NTDs, the unique aspects of NTD programmes, and the opportunities outlined above for integration of mental and physical healthcare all serve as important contributions to the global mental health community and should be shared. The finding that NTD research is not currently featured in the global mental health online research repository, **Mental Health Innovation Network (MHIN)**^{iv}, suggests that further links can and should be made.

It is in the context of the aforementioned challenges that the MWS task force of the NNN has been established and currently convenes on an annual basis. At the time of writing, significant progress has been made on a key intervention manual created in collaboration with WHO, which is due to be published in 2019. Furthermore, a session at the **Coalition for Operational Research on Neglected Tropical Diseases (COR-NTD)** meeting in Baltimore in November 2017 was focused on the identification of a research agenda for the task force. A list of research priorities was created in the session and were refined by key actors in the field (see Outstanding Questions), paving the way for further progress and future partnerships in this important area.

Acknowledgments and Disclaimer Statement

D.H.M. acknowledges the financial support of Sanofi and declares a potential conflict of interest. D.H.M. and F.B. acknowledge the financial support of Sightsavers and declare a potential conflict of interest.

Resources

ⁱwww.infondt.org/biblio_search/search

ⁱⁱwww.infondt.org/keytopic/stigma-and-mental-health

ⁱⁱⁱwww.bsms.ac.uk/research/global-health-and-infection/nih-global-health-research-unit-for-ntds/nih-work-packages.aspx

^{iv}www.mhinnovation.net/resources

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