



**Voices and Perspectives of Communities Affected by Chronic
Kidney Disease of Unknown Etiology**

A Briefing Paper

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Anushka Kahandagama, Naveen Maha Arachchige and Nusrath Perveen from LST visited the affected areas and conducted interviews

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Introduction

Chronic Kidney Disease of Unknown Etiology (CKDu) is concentrated in the North Central Province of the country but its prevalence is now recorded in many others parts of the country. According to a Presidential Task Force focused on CKDu, 60 Divisional Secretariat areas across 10 districts are considered affected, some severely and as of December 2014, there were 40,680 patients officially registered as having been affected by CKDu.¹

In the course of our engagement with supporting the land and economic rights of poor rural agricultural communities, the experiences and perceptions of CKDu-affected communities regarding its effects and causes and the efficacy of or gaps in state response was underlined as important to document further. It is in this context that the Law and Society Trust (LST) is issuing this Briefing Paper.

This Paper documents experiences of some affected communities from the districts of Badulla, Mahiyanganaya and Monaragala. It draws on a field mission to affected communities and interviews with patients and family members, other members and leaders of local communities, health practitioners, researchers and scientists, and others. In addition to those engaged in paddy cultivation, the communities visited by LST included those engaged in horticulture and sugarcane cultivation.

Causes of the Disease

A number of different factors have been identified as being amongst the causes of the disease. Contamination of water by agro-chemicals is one that is most widely acknowledged as a prime culprit. However not all experts agree with this, according to Prof. Dissanayake from the

¹ Presidential Task Force on Chronick Kidney Desease Prevention. See <<http://www.presidentialtaskforce.gov.lk/en/kidney.html#>>. accessed on 16th Nove.2016

University of Peradeniya,² toxin-releasing algae in water tanks³, widespread in affected areas, is a likely cause.

Habitual alcohol consumption, food habits and prolonged exposure to heat are also identified as factors that enhance vulnerability to the disease.⁴

According to a health practitioner in Girandurakotte in Mahiyanganaya:

‘People’s first priority is paddy cultivation. During the harvest season farmers do not get any time to relax but work day and night for two weeks. In this period farmers do not consume proper meals or water but work under the sun for a long time. They sweat a lot and urine output is low. Farmers who work in the paddy fields in the hot sun do not have a can of water around their necks (Health Practitioner from Girandurakotte)

According to Dr. Gamini Hitinayake⁵ from Peradeniya’s Faculty of Agriculture, another important factor precipitating CKDu is the nature of the soil. Microbes and natural nutrients of the soil have been destroyed due to large-scale indiscriminate use of agro-chemicals especially fertilizers. As a result, the soil in many area has not only lost its capacity to ‘purify’ water by absorbing certain harmful elements but is itself contaminated by chemicals. High groundwater fluoride content⁶, leaching of heavy metals such as cadmium, arsenic from chemical fertilizers into

² Interview with Prof. Dhammika Menike Dissanayake, on 2nd May 2016

³ *Wewa*

⁴ Interview with Prof. Dhammika Menike Dissanayake, on 2nd May 2016

⁵ University of Peradeniya

⁶ Chandrajith R, Nanayakkara S, Itai K, Aturaliya TN, Dissanayake CB, Abeysekera T. Chronic kidney diseases of uncertain etiology (CKDu) in Sri Lanka: geographic distribution and environmental implications. *Environ Geochem Health* 2010; Sep 18.

water sources⁷ are also recognized as important contributing factors to the disease. As the health practitioner from Girandurakotte, cited above, said:

‘Either you drink the water or not, either way you will die’

According to the Presidential Task Force on Chronic Kidney Disease Prevention, “the disease is attributed to several causative factors including high use of agrochemicals, hard water which include high levels of Calcium and Fluoride, dehydration due to inadequate drinking of water and heat, and presence or absence of certain chemical compounds (eg. high levels of Arsenic and Cadmium, low levels of Selenium).”⁸ Interviews with affected individuals and communities as well as others in the CKDu prone areas covered by this Briefing Paper underline that agro-chemicals is the most widely perceived as the most implicated of all possible causes.

Like many other countries, Sri Lanka’s path to development has often been insensitive to environmental impacts and their human costs. The Mahaweli project was initiated decades ago with the twin objectives of power generation and irrigated agriculture (Muller and Hettige 1995). After years of implementation, including an intense phase of acceleration when feasibility researches were also not undertaken, the Mahaweli project has started showing its negative impact in many aspects.

Ninety five per cent of the first generation of Mahaweli settlers have been killed due to the disease [CKDu]. Earlier these were forest areas. Due to the accelerated Mahaweli project the forests were destroyed and

⁷Bandara RS, Senevirathna DMAN, Dasanayake DMRSB. Chronic Renal Failure among farm families in cascade irrigation system in Sri Lanka associated with elevated dietary cadmium levels in rice and freshwater fish (Tilapia). Environmental Geochemistry and Health 2008; 3:465- 478.

⁸Presidential Task Force on Chronick Kidney Disease Prevention. See <<http://www.presidentialtaskforce.gov.lk/en/kidney.html#>>. accessed on 16th Nove.2016

flattened using bulldozers. People destroy the environment in the name of development. But if the environment cannot bear it, environment destroys people. As we have destroyed the environment people should expect its consequences. Mahaweli was developed by some, benefitted some others but it negatively impacted on poor farmers. People are paying with their lives (Medical Practitioner, Girandurakotte).

According to Muller and Hettige, consequent soil erosion and increased destruction of forest caused ecological damage that cannot be reversed by any re-forestation activity (1995: 14). Connected to these ideas, it is suggested to further investigate the Mahaweli development project in relation to the prevalent chronic kidney disease (Bandarage 2013 and Chandrajith et al 2011).

The lack of monitoring has been compounded by the fact that various administrative bodies functioning in the area including Mahaweli Authority, local government authorities, and various departments and people are uncertain about the relevant authorities to contact in order to solve their problems. The brushing aside of state responsibility to address the problems emerging as a result of the Accelerated Mahaweli Development Project has escalated the problems and worsened living conditions of the people.

Farming communities who reside in the affected areas are highly confused about the reasons of the disease. While they are unconditional in their cry for clean water, confusion caused by authorities as well as researchers are prevalent among the communities.

We don't know what the exact cause of the disease is. Earlier they (authorities) they said it's due to the use of Aluminum pots we used to cook in. Then we

changed it. Then they said it is because of the agro-chemicals. After that they said it is due to the contaminated water and alcohol consumption. We are not in a position to tell exactly as we don't know' (A farmer from Aluyatawala).

While the above statement is suggestive of the confusion prevalent among affected communities, it also highlights a fear of expressing their ideas against the 'scientific knowledge', which in fact has not proven to be reliable in pinpointing or isolating a single cause.

The political economy of CKDu

Chronic kidney disease has been widely discussed in Sri Lanka for years through many perspectives but primarily from a medical⁹, sociological,¹⁰ and geological¹¹ standpoint. While natural scientists are interested in its etiology, i.e. causes, social scientists are interested in analyzing the social, political and economic conditions that have precipitated the disease and its impacts. However, notwithstanding significant amount of research, into the disease and its aftermaths, policy responses with regard to possible preventive measures continues to be weak.

⁹Handunnetti, D. and S. Daniel (2012). "Conflicting reports highlight scientific data gaps in Sri Lanka's chronic kidney disease". SciDevNet. Available online: <http://www.scidev.net/en/south-asia/features/conflicting-reports-highlight-scientificdata-gaps-in-sri-lanka-s-chronic-kidney.html>.

¹⁰Liyanage, C. 2015. Policy Aspects in Addressing Chronic Kidney Disease of an unknown/uncertain etiology, in LST Review, Addressing CKDu-an Ongoing Challenge for Sri Lanka, June 2015., Liyanage C. 2009. Chronic Kidney Disease with Unknown Etiology: The discourse, lay perception, behaviour and coping mechanisms, Colombo, National Science Foundation.

¹¹Perera, A. (2012). "Study links kidney disease in Sri Lanka's farm belt to agrochemicals". Inter Press Service. Available online: <http://www.ipsnews.net/2012/08/study-linkskidney-disease-in-sri-lankas-farm-belt-to-agrochemicals/> PML/PR-42/2012.

The political economy of the disease is of great significance. Apart from the fertilizer subsidiary being a political promise made in the elections, sustainable agricultural policies are being poorly attended to by the State (Prematunga 2016).¹² Findings from the research suggest that the State Agrarian Officers are both inaccessible and inefficient, they also do not have sufficient knowledge to inform people about sustainable farming methods. Indeed, these officials are largely products of a knowledge system that promotes chemical intensive green revolution rather than sustainable agrarian methods.

In the absence of support and guidance from agrarian officers regarding the use of agro chemicals and fertilizers, we found farmers relying on advice from retailers of these products. According to an informal interview with an agro-chemicals retailer, they tend to encourage farmers to buy products of agro-chemical companies that are most profitable or otherwise incentivized. In other words, not only is the market mechanism determining farmers' choices but agricultural practices themselves are largely supplier driven and determined. Further, while Government officials are silent in providing knowledge about sustainable farming methods or precautionary methods of using agro chemicals and fertilizer, agro-chemical companies are conducting awareness programmes for the farming communities.

Instead of individual farmers, farming companies are spreading throughout the country. According to an interview with a member of the Movement for Land and Agricultural Reform (MONLAR):¹³

¹²Prematunga, S. 2016. Political Agenda Rooted in Agricultural Policy. Weekend Nation.<http://nation.lk/online/2016/10/22/political-agendas-rooted-in-agriculture-policy.html>. The web site of the Ministry of Agriculture displays two policy documents that are markedly different though both stress the need for sustainable agricultural methods. However, there is a fracture between the written agricultural policy of the country and its implementation and functioning.

¹³Movement for National Land and Agricultural Reform

Farming companies are expanding. already have large Cavendish Banana plantations in Demaliya, Kuda Oya and Demodara, all belonging to the Uva province. They are expanding their plantations in Gonagan-Aara and Mahiyanganaya.is about to start a plantation in Polonnaruwa district and is about to start a new plantation in Monaragala. have plantations in Kandakatuwa, Polonnaruwa District, and export their yield through Another farming company, ‘..... company’, is coming up in Kotiyagala having acquired 2500 acres of land from the farmers.

Inquiries from the Ministry of Agriculture revealed that such statistics regarding the expansion of these companies are unavailable. Moreover there are serious concerns regarding the agricultural practices of these companies. Speaking about Dole Lanka at a recently concluded Peoples’ Tribunal on Agrochemical Transnational Companies, an activist from Monaragala, Ms. Somalatha¹⁴, said the company uses agrochemicals that can't be found in the local market and are extremely toxic. According to her the workforce is exposed to these chemicals throughout the day and as a result most of the women workers suffer from a number of serious health issues, including chronic pain in the back and knees, liver issues, anaemia, miscarriages and children with birth defects.¹⁵

In so much as the discourse on awareness raising and regulation of the use of agro-chemicals is heavily focused on individual farmers, it actually makes them responsible while the practices of multi-national or local agri-businesses and farming companies are rendered out of sight. In many respects therefore CKDu emerges as a condition linked, on the one hand,

¹⁴ Ms. Somalatha is the president of Uva Wellasa Women’s Rights Association, Wellawaya, Monaragala.

¹⁵Peoples’ Tribunal on Agrochemical Transnational Companies - Final Report, 2016.Law and Society Trust, Movement for Land and Agriculture Reforms, and the National Movement against Poisons.

to a particular bias in state policies in favour of intensive industrialized and chemical-dependent agriculture, and on the other hand, a steady weakening of the state and its institutions in favour of market forces masked by a rhetoric and apparatus of state support. Both of these tendencies have well-known adverse consequences for health and the environment.

As preventive measures, the Presidential Task Force on Chronic Kidney Disease Prevention suggests,

1. Screening for early detection of the disease through selected communities;
2. Strengthening of the four curative areas of intervention:
 - a) Expanding primary health care centres
 - b) Ensuring nephrologists visit health centres
 - c) Equipping hospitals with dialysis facilities
 - d) Setting up nephrology centres
3. Introduction of CKD/CKDu surveillance and patient registries in high-risk areas; and,
4. Providing financial assistance to CKD/CKDu patients.¹⁶

However, the identified causes of the disease are not really directly addressed by the preventive measures identified by the Presidential Task Force. Most of these measures are not 'preventive' but post-facto measures for those already affected by the disease. They mostly amount to promises of medical facilities, the establishment of which is often caught up in the dynamics of political patronage.

¹⁶Presidential Task Force on Chronic Kidney Disease Prevention. See <<http://www.presidentialtaskforce.gov.lk/en/kidney.html#>>. accessed on 16th Nove.2016

Key concerns emerging from field mission

Lack of access to safe and clean water

Rathkinda in Mahiyanganaya is a village under the Mahaweli Authority. A discussion with farmers from the village revealed that it is severely affected by CKDu. As water is one of the basic needs and its contamination is identified as one of the primary causes of the disease, the previous government had started a water project. But although six years have passed, the project is still only halfway and at present not progressing at all. While the village was allocated a well under the *Gami Diriya* and work has begun the Mahaweli Authority has stopped the project.

‘The Health Department only provided water filters after you got sick; not before. But now, they are not providing water filters at all’ (CKDu affected farmer from Rathkinda).

Preventing the disease was one of the major concerns of the people interviewed. Although contaminated water is not identified as the sole source of the disease, access to safe and clean drinking water is a basic human need. Thus, most of those interviewed demanded access to clean water. Rathkinda is an example of how the State has failed in providing a basic need to the people and has been unsuccessful in clarifying and resolving the administrative bottlenecks that hinder provision of water.

While some of those affected by CKDu are given a water filter by the government this does little by way of prevention. In order to provide clean water for the people it is suggested to build water purification systems or provide water filters to the families. Further, it is proposed to provide a mobile service to test the condition of the water and identify the clean water sources.

Lack of Social Security and Economic Support

Normally people get 5 bushels of paddy from 2.5 acres. When the bread winner gets sick, they sell one bushel first and they start treating the person through exorcism. After practicing this, the patient feels much better as it helps the patient psychologically. However, when we identified a patient we send him/her to the renal unit, Kandy. If the patient is in a bad condition it is necessary to start dialysis. When they do dialysis for the first time, the government provides it for free. But when the conditions gradually become worse and the patient needs dialysis two or three times per week, the state only provides partial support to the patient, saying that some of the services, should be bought by the patient. After going through this process, the affected family becomes poorer and poorer as they have to sell their paddy land gradually to treat the patient and in the end for the funeral. There is no one to talk about welfare of the family of the patient. (Medical Practitioner Girandurakotte).

There is no social security for us (Farmer from Rathkinda)

'State gives a small amount of money for the patients who are in the last stages of their life due to the disease. It is like a tip. Previously this amount was 1000 LKR per month, but they have increased it to 3000 LKR. This is a joke. State thinks that this is a huge amount of money for a CKDu patient. But it is not. The patient does not spend that money on treatments as he or she knows that this is the last stage of his or her life. Thus, he or she buys some food and eats with the family. If the person is

addicted to liquor, that person consumes liquor (Medical Practitioner Girandurakotte).

There is no point of providing only training. There should be a way for us to sell our products. There should be a market (Wife of a patient, Aluyatawala).

In a scenario where preventive measures are scarce, there is little hope for socio-economic security of the patient and his/her family. Once identified as a person affected by CKDu, the government's assistance includes provision of a water filter to the family and an allowance of Rs.3000 per month when the kidneys of the patient are reduced to working below 20 percent. As it is often the breadwinner who is affected by the disease, the socio-economic condition of the family worsens. The economic problems lead to other social problems, even social stigma and in critical cases to suicide.

Some family members called for opening up opportunities in self-employment by providing training and a market for their products. Further, awarding monetary compensation to the families who have lost the breadwinners was also advocated.

CKDu also has gendered effects in terms of the additional burdens it imposes on the women both to render care as well as assume responsibility for the household.

The man is the one who gets affected by the disease. The woman remains, and then has to engage in menial labour work to survive (Family member of a patient, Aluyatawala).

is a beautiful young woman. Husband died due to the kidney disease. People try to misuse her. She pawns her paddy land. Then starts working at a garment factory. Her daughter is young. Daughter eloped with a boy

when she was 15. Then she comes back home at the age of 17 with a child. Both mother and daughter becomes prostitute. When mother came to know that her daughter has become a prostitute, mother committed suicide (Teacher from Girandurakotte).

It is clear that CKDu is inducing multiple crises within affected communities and accentuating existing economic and social vulnerabilities.

Lack of Medical and Psycho-social support

Patients do not have enough health facilities. They do not have the facility to check whether they are affected or not. Government does not provide any screening test clinics to check whether people are affected or not. There is one hospital for eight villages with 3000 people (Medical Practitioner Girandurakotte).

There are medical clinics for screening the disease. But these clinics are only held once in a year or two (CKDu affected farmer from Rathkinda).

Generally, people are suffering from un-employment, poverty, lack of access to education and infrastructure facilities. Under these conditions, the access to health facilities are limited and sometimes people have to travel far to get medical treatments. Mobile clinics and intense surveillance and increasing accessibility to health services are critical.

Patients or families do not directly make references to the need for psycho-social support. However, it is clear that patients and family members suffer in multiple ways that burden them psychologically. It is clear that patients need proper medical treatment along with psycho-social support to cope with their situation.

We met and interviewed persons affected by CKDu from Lindaragama in Badulla, which is a sugar cane area. One of them had a dialysis tube and breathing problems while most of them could not talk properly due to their critical health condition. From the way they showed their medical reports and prescriptions or the dark patches on their feet and body, it was obvious that they were desperate with their situation. None of them showed a glimpse of a smile.

Lack of knowledge of sustainable farming

Earlier there was a proper mechanism to inform people about farming methods through agrarian officers, etc. However, at present these networks have collapsed. There are no officers to go to the field and share knowledge with the people. Although there are lots of officers appointed by the state, they have to do a lot of paper work regarding fertilizer distribution and other administrative work (Medical Practitioner, Girandurakotte).

Government has recruited young people for jobs [agrarian officers]. They do not have proper [practical] knowledge. They only have bookish education. As officials do not have knowledge there is no point in them coming to the village (Female farmer from Mahiyangana).

These officers do not have any knowledge about farming. Earlier if there was any disease, farmers go to the agrarian officer or Mahaweli officer. But things have changed and farmers go to the fertilizer and pesticide dealers [for advice]. Then the shop-keeper decides what kind of pesticide should be utilized in the

paddy fields Farmers do not use masks and other methods. These people are not traditional farmers. As most of these settlers are from the hill country and new to these villages they do not have any knowledge on traditional farming methods. Further, people who have settled in these areas are not primarily farmers but people who had connections with politicians in their respective areas. (Medical Practitioner Girandurakotte).

Farmers do not follow precautionary measures. People are careless. Farmers eat beetle and smoke beedi when they are spraying pesticides to the paddy field (Female farmer from Mahiyanganaya).

No one is coming to raise awareness among farmers (Farmer from Rathkinda)

It was found that, although most of the farmers do like to practice traditional farming methods, there are some obstacles. Firstly, most of the farmers do not have sufficient knowledge regarding traditional farming methods as they were settlers or first generation farmers relocated under the Accelerated Mahaweli Development project and did not have a history in agriculture. Secondly, technologically developed hybrid seeds are not conducive to traditional farming methods. Thirdly, as agrarian service officers are products of a knowledge system that has privileged chemical farming, they do not possess knowledge regarding traditional farming methods. Thus, there must be traditional sustainable knowledge systems on farming and dissemination of knowledge through proper networks.

The weak relationship between agrarian officers (belonging to both the Department of Agriculture and Mahaweli Authority) and farmers was repeatedly pointed out. As most of these officers are not available in the villages, farmers often go to retailers of agro-chemicals for advice on

farming practices. It is vital to improve accessibility to the knowledge of traditional farming practices not only amongst the community also amongst officials, especially agrarian service officers. Equally there must be t more effective regulation of the existing system of agrarian support.

State Responsibility and CKDu: The Lanka Sugar Company Plantation in Pelwatte

The Lanka Sugar Company—under the Ministry of Industries and Commerce but managed by the Ministry of Plantations—maintains a settlement scheme for farmers in Pelwatte, Monaragala. According to the company’s website,

*‘The settler area consists of 4024 hectares. Lands are divided into plots of 1.75 ha which are leased to individual settlers and 0.25 ha allocated for his homestead. The company purchases their crop of sugar cane at pre-determined prices under a forward sales contract’.*¹⁷

A focus group interview with 15 farmers, including men and women, affected by CKDu revealed the extent to which the state is directly complicit in practices that have directly precipitated the disease. The company provides fertilizer and pesticides, the costs of which it recovers from the farmer’s earning from the yield. Farmers said they are also not allowed to cultivate any other crop or are not allowed to sell their yield to anyone else but the company.

They see a direct link between being compelled to grow sugarcane and the disease. As one middle-aged farmer said,

¹⁷Lanka Suger Company Ltd, Pelwatta, <http://www.lankasugar.lk/pelwatte/index.php/settlement-scheme>. Accessed on 21st November 2016

We did not have any disease earlier. After the plantation started, we became sick.

We use pesticides and fertilizer. Government officers do not raise awareness. It is the company that distributes pesticides and fertilizer, but they recover money for that from the earnings of the yield.

Farmers are indebted to the company since the land belongs to it. Although the disease has affected the farmers, the company does not provide any financial or medical aid. As another one of the farmers said:

People are in a desperate situation. Farmers have become indebted to the company forever. Although farmers work hard every day there is nothing left for the farmer at the end of the day. The company does not spend even one rupee for the sick farmer.¹⁸

This farming community is trapped in a never ending vicious circle of poverty, and as a result, ill health.

The Company doesn't do anything after we get the sick. When the man gets sick, other family members have to work in the farms, otherwise we can't repay the debts to the company. So someone has to work in the fields. The Company doesn't care about us. It only tries to recover debts from us even if we died. If we are unable to repay, the Company takes the land from us. There is no profit for us after paying all the debts to the Company.¹⁹

It is ironic that a fully State-owned company is itself sustaining political economic conditions akin to bonded or forced labour and agricultural

¹⁸ Farmer 2, male, middle age

¹⁹ Farmer 3, male, middle age

practices that are clearly harmful. The cleavage between State policies to address CKDu and the farming practices of the State is having deadly consequences. The latter, which are located in a development paradigm that is exploitative and solely profit oriented, are a far cry from the rhetoric of sustainability. The ‘unknown’ nature of its etiology is being leveraged for political and economic advantages, particularly to allow the Company to ignore the plight of CKDu affected farmers.

Conclusion and Recommendations

Irrespective of the fact that the etiology of CKDu remains contested, it is as much a political economic phenomenon as it is a pathological medical condition. It is the direct outcome of set of political economic relations of development shaping land use and agriculture. While there is little doubt that large-scale state-led interventions like Mahaweli development are deeply implicated, CKDu is a product of particular intersection of state and market forces, especially agro-chemical and seed companies, that has shaped the political economy of agriculture.

There are therefore many dimensions to state responsibility in this regard, from persisting with agricultural policy that privileged productivity at any cost, especially through intensive use of agro-chemicals, to weakening and inappropriate support for farming communities to poor public provisioning of preventive, screening/diagnostic, and curative health services as well as safe and clean water. There has also been a failure to regulate the toxic nature, marketing and use of agro-chemicals, the lack of accountability has meant that private profits from agrochemical have accrued while the costs have been socialized.

A combination of all of the above has trapped farming communities, many of them first generation Mahaweli settlers with little or no history of agriculture, into a path of dependency. This has been reinforced by the

lack of empowerment in terms of knowledge and information as well as a short-termism with respect to productivity.

The current policy response does not seem to be informed by a clear understanding of the social and economic crises related to CKDu. While areas have been classified as being highly/severely, moderately and mildly affected, a commensurate state response in these areas in terms of screening, preventive and curative measures are not visible. The disease is only amplifying fault lines such as gender and class, thus creating new vulnerabilities or amplifying existing ones. The impoverishment effect of the disease is also closely linked to the absence of adequate social security.

Given the above, the following short-term measures emerge as priorities from the perspective of affected communities:

- Provide effective water treatment and purification measures to communities and neighbourhoods where there is a prevalence of CKDu.
- Enhance the financial and psycho-social support to families affected by CKDu.
- Ensure immediate access to treatment and diagnostic services and drugs for all affected persons at state expense through public or private hospitals.
- Take immediate measures to protect affected families who are particularly vulnerable, such as female-headed households, from multiple risks by providing adequate social security measures.

At the same time as the above measures are taken, the following measures also emerged as important:

- Enhancing and expediting screening of water as well as populations to identify vulnerable areas and communities more widely across affected regions.
- Undertaking a time-bound, speedy and comprehensive review of the agricultural policy as well as health services and infrastructure in affected or vulnerable areas to identify and undertake remedial measures.
- Initiating a livelihoods support and assistance plan that is effective and responds to the needs and constraints of affected individuals, families and communities.

Finally, in cases such as Pelawatte plantations there is a direct responsibility of the State for which it must be held accountable. It is clear that while the President and other parts of the State are speaking the language of sustainability and good governance, the reality for farmers virtually trapped in this situation is tragically different.

Date	Interview	Place	Type of Interview	Participants	Time
4/5/2016	Interview with key informants	Peradeniya (kandy)	In-depth Interview	Dr.GaminiHitinayake	12.30 PM -2.20 PM
			In-depth Interview	Dr.DammikaMenike	2.45 PM – 3.35 PM
	Young Farmers Association (04 people, middle aged, one female and three males)		Focus Group Interview		4.00 PM-4.40 PM
5/5/2016	Health Practitioners	Bathalaya (Mahiyang anaya)	In-depth Interview	Medical Practitioner (middle age male pharmacist)	11.00 PM-1.110PM
			In-depth Interview	Medical Practitioner (young male doctor)	2.00 PM-2.30 PM
	Affected groups (Family Members)	Aluyatawela (Mahiyang ana)	Focus Group	1. School principal (middle age, male) 2. wife of deceased from CKDu (young, female)	3.15 PM-4.40 PM

				<ul style="list-style-type: none"> 3. Family member of a patient (young, female) 4. Farmer affected with CKDu (old, male) 5. Wife of deceased (young, female) 	
	Farmers	Rathkinda (Mahiyangana)	Focus Group	<ul style="list-style-type: none"> 1. Buddhist monk who has donated the kidney to a CKDu patient (Middle age, male) 2. Farmer (Middle age, male) 3. Farmer (Middle age, male) 4. CKDu affected farmer (middle age, male) 	5.30 PM -6.35 PM
6/5/2016	Community members	Sarvodaya - Mahiyangana	Focus Group	<ul style="list-style-type: none"> 1. Police officer (male, middle age) 2. Police officer (male, middle age) 3. Sarvodaya Officer Mahiyangana (Female, middle age) 4. Businessperson (Female, middle age) 5. Farmer (female, middle age) 	10.05 AM-12.10 PM

				<ul style="list-style-type: none"> 6. Retired Government Servant (male) 7. Farmer 2 (female, middle age) 8. Officer – Govi Jana Sewa (female, middle age) 	
	Activists	Sarvodaya -Badulla	Focus Groups	<ul style="list-style-type: none"> 1. UCDC member (male, middle age) 2. Sarvodaya officer (male, middle age) 3. Doctor (Activist, young male) 4. Activist (male, middle age) 5. Activist 2 (male, middle age) 	5.30 PM-7.10 PM
7/5/2016	Farmers	Silgampol a	Focus Groups	<ul style="list-style-type: none"> 1. Farmer (male, middle age) 2. Farmer (male, middle age) 3. Agrarian Officer (male, middle age) 4. Farmer (male, middle age) 5. Secretary-Citizens forum (Male, middle 	9.40 PM – 10.57 PM

				age)	
	Activist	Govi Jana Center-HaliEla	In-depth Interview	1. President – Citizens Forum (Male, middle age).	1145-2.10 PM
	Patients	Lidara Gama-sector 3	Focus Group	15 - males 9 females 2 all were middle age An activist (Female, middle age)	
11/11/2016	Activist	MONLAR		Male	

'When we were children, farmers used to worship the gods prior to start working. They start after lighting up the lamps. Farmers start work after worshipping the hoe. That is the spiritual side of the people. Today we have lost that. The first five precepts of Buddhism are 'prevention of homicide'. But now, we do that [killing of animals] as the first thing when we start farming. We spray poison [agro chemicals] on the paddy field. Then we turn the field into a graveyard. We kill all the visible and invisible animals. Then the farmer starts working in there [poisoned paddy field]' (Sarvodaya Officer, Badulla who has worked immensely to prevent the CKDu)

Irrespective of the fact that the etiology of CKDu remains contested, it is as much a political economic phenomenon as it is a medical condition. There are many dimensions to state responsibility in this regard, from persisting with agricultural policy that privileged productivity through intensive use of agro-chemicals—resulting in private profits but socialization of its costs, weakening and inappropriate support for farming communities and poor public provisioning of preventive, screening/diagnostic, and curative health services as well as safe and clean water. There has also been a failure to regulate the toxic nature, marketing and use of agro-chemicals; the lack of accountability has meant that private profits from agrochemicals have accrued while the costs have been socialized.

The current policy response does not seem to be informed by a clear understanding of the social and economic crises related to CKDu. The disease is only amplifying fault lines such as gender and class, thus creating new vulnerabilities or amplifying existing ones. The impoverishment effect of the disease is also closely linked to the absence of adequate social security.

Provide effective water treatment and purification measures to communities and neighborhoods where there is a prevalence of CKDu, enhance the financial and psycho-social support to families affected by CKDu, ensure immediate access to treatment and diagnostic services and drugs for all affected persons at state expense through public or private hospitals, and take immediate measures to protect affected families who are particularly vulnerable, such as female-headed households, from multiple risks by providing adequate social security measures are the key suggestions.