



# Modelling Nodding Syndrome: System Dynamics Approach

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## ABSTRACT

The emergence of nakalanga syndrome in the 1960s (Colebunders *et al.*, 2014), now known as nodding syndrome, whose causes, diagnosis and treatment are not well established (Buchmann, 2014; Idro *et al.*, 2016), has provoked a lot of both social and scientific theories and discourses both nationally and internationally. It is a devastating neurological disorder (Idro *et al.*, 2013) that makes an individual experience seizures, developmental retardation and growth stunting (Dowell, 2013). This atonic seizures causes characteristic rhythmic dorso-ventral “nodding” of the head and comorbidities include but are not limited to: psychological and behavioural abnormalities, malnutrition, cognitive decline and other seizure types (Gazda, S. *et al.*, 2015; Kitara, 2015). It is an epidemic epileptic encephalopathy of unknown cause, that has affected an estimated thousands of children (Buchmann, 2015). It results to severe socioeconomic implications. Just like other forms of epilepsy, it is associated with social stigma. Many children have died as a result of uncontrolled seizures that have led to drowning or burning (Idro *et al.*, 2013).

### How Modelling May Aid Understanding Nodding Syndrome

Since the aetiology, risk factors, climatic and socio-demographic effects of nodding syndrome is/are not well established, it is important to model the attributes to bring out more understanding of the ailment affecting children at epidemic scale especially in Northern Uganda. Modelling has always been an important part of understanding systems (Krogstie, 2007). It has emerged as a means to capture the relevant aspects of the world on which it is necessary to provide information (Rolland, 2007). It promotes the scientific understanding and guides data collection in the sense that, scientifically, a model is a representation of hypothesis about a system under investigation and enables a comparison between hypothesis and data (Zawedde, 2016). Conceptual models are used to create a representation that aids in the understanding of the problem domain (Bera *et al.* 2010).



Source: A Nodding Syndrome victim in Northern Uganda. PHOTO/Edward Echwalu

## METHODS

**Method:** Systematic review of literature was used and Boolean operators to extract relevant literature using aggregator Libhub that auto selected science direct as preferred search engine. We have used system thinking (system dynamics) methodology and vensim software to build the socio-scientific response model and express the relationships..

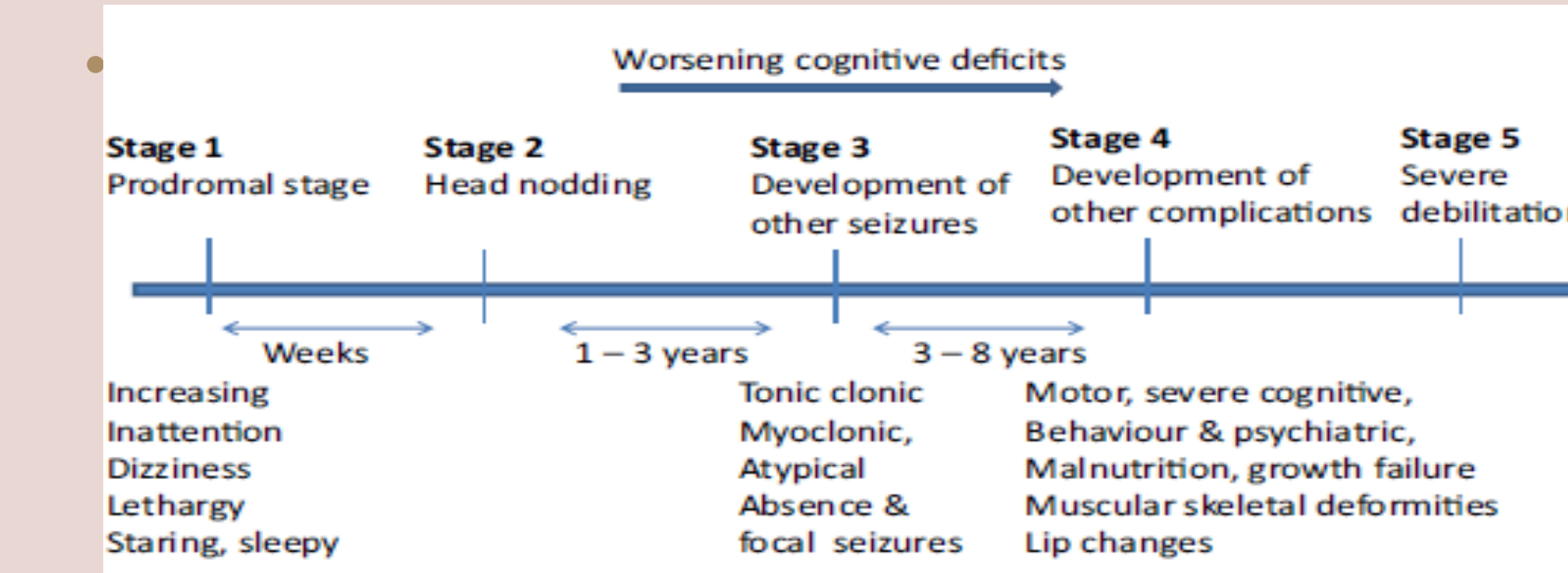
## PAPER REVIEW RESULTS

In all the literature reviewed, none of them used system dynamics to investigate how scientists and community responded to the challenge of nodding syndrome whose causes are not well understood. We explored the role of both *social* and *scientific* responses to nodding syndrome. Findings were represented using causal-loop-diagrams (system dynamics approach).

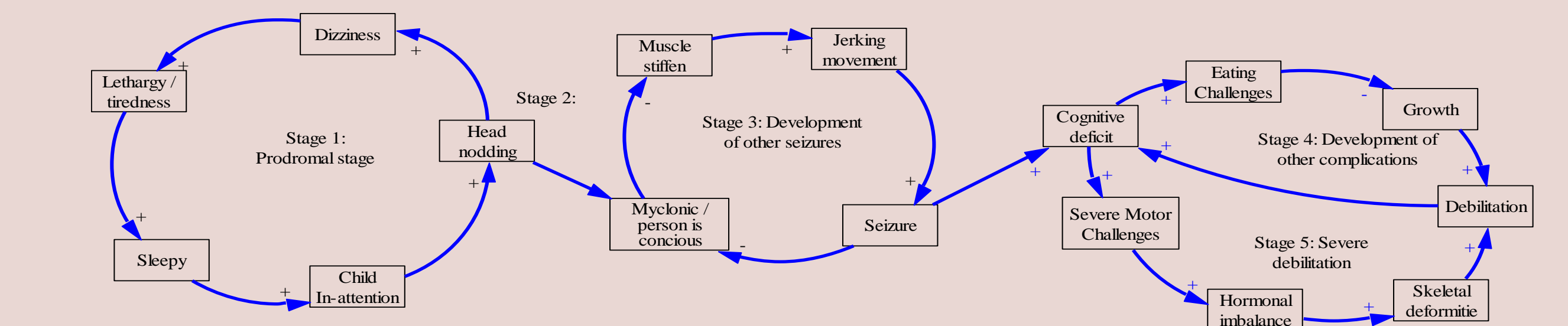
Sn	Article Details	Has Conceptual Model	Use System Dynamics in the Model	Has other Models
1	Nodding syndrome, other forms of epilepsy, and the Nakalanga syndrome most likely directly or indirectly caused by <i>Onchocerca volvulus</i>	-	-	-
2	Environmental, dietary and case-control study of Nodding Syndrome in Uganda: A post-measles brain disorder triggered by malnutrition? Peter S. Spencer <i>et al</i>	-	-	Map & Graph
3	Nodding syndrome: 2015 International Conference Report and Gulu Accord P.S. Spencer, D.L. Kitara b, S.K. Gazda c, A.S.Winkler	-	-	-
4	Is nodding syndrome an <i>Onchocerca volvulus</i> -induced neuroinflammatory disorder? Uganda's story of research in understanding the disease Richard Idro <i>et al.</i>	Yes	-	Maps
5	Neurophysiological and clinical findings on Nodding Syndrome in 21 South Sudanese children and a review of the literature Gianni de Polo <i>et al.</i>	-	-	Table & EEG
6	These nodding people': Experiences of having a child with nodding syndrome in postconflict Northern Uganda Kristine Buchmann	-	-	-
7	Nodding syndrome—a new hypothesis and new direction for research Robert Colebunders <i>et al.</i>	-	-	Graph
8	Nodding Syndrome in Onchocerciasis Endemic Areas R. Colebunders,1,* A. Hendy,2 and M. van Oijen,1,3	-	-	Graph
9	Nodding syndrome in northern Uganda: Overview and community perspectives Katrina B. Mitchell <i>et al.</i>	-	-	-
10	Reviewing the evidence on nodding syndrome, a mysterious tropical disorder Danie I Arnoldus Korevaar	-	-	-
11	Editorial Nodding syndrome—we can now prevent it	-	-	-
12	Uganda: how goes the nodding syndrome war?	-	-	-
13	The nodding syndrome: A new form of epilepsy? R. Idro	-	-	-
14	Clinical, neurological, and electrophysiological features of nodding syndrome in Kitgum, Uganda: an observational case series James J Sejvar, <i>et al.</i>	-	-	EEG
15	Nodding syndrome—a challenge for African public health	-	-	-
16	WFN15-1813 Environmental Neurology T 20.1 Nodding Syndrome: an epileptic disorder restricted to Africa? P. Spencer.	-	-	-
17	CDC planning trial for mysterious nodding syndrome, world report	-	-	-
18	Detection of auto-antibodies to leiomodin-1 in patients with nodding syndrome Tory Johnsona,	-	-	-
19	Nodding syndrome; a new (infectious?) disease entity of the CNS in Eastern Africa R. Idro.	-	-	-

## DERIVING SYSTEM DYNAMIC MODELS FROM CLINICAL MODEL

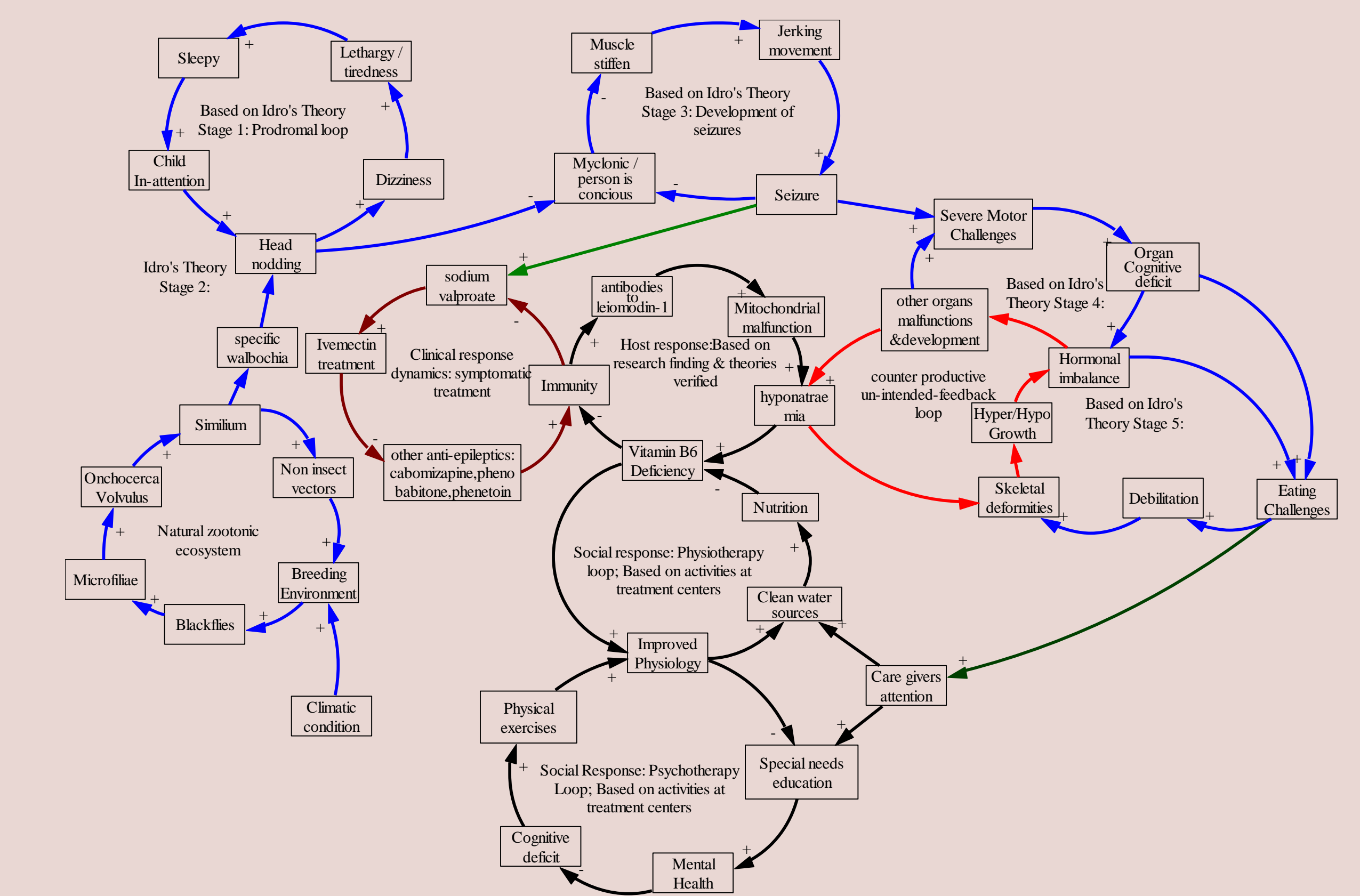
- *Idro's Five distinct but overlapping clinical stages over several years (Idro *et al.*, 2016) and corresponding System Dynamic Modelling of Idro's Stages of Nodding Syndrome*



### Idro's Model Using Systems Dynamic Approach



### Socio-Scientific Response Model to Nodding Syndrome



## PURPOSE

The *Aim* of this study is to model social and scientific responses to nodding syndrome mystery.

## OBJECTIVES

- 1) To investigate whether system dynamics modelling techniques have been used in conceptual modelling of nodding syndrome.
- 2) To investigate the social and scientific response to nodding syndrome.

## CONCLUSIONS

1. There was no encounter of system dynamic modelling of nodding syndrome response from both social and scientific literatures.
2. Literature hardly considered modelling as an important aspect of understanding the mysterious disease called nodding syndrome.
3. The ailment challenges especially in Northern Uganda provoked both social and scientific response although aetiological factors are not well understood.
4. Both social and scientific responses resulted to improvement in the livelihood of children infected with the disease. Social response were very important reinforcement to scientific investigations. And both approaches contributed to the improvement of immunity of affected individuals.
5. The model derived 9 causal-loops in nodding syndrome pathogenic pathways and responses being provided