A Sierra Leonean Approach to Sickle Cell and

Inclusion

A Guide to School Policy

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We would like to thank the following for their work in producing this adaptation of the Guide to School Policy:

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Benson A. Sesay, Freetown Secondary School for Girls
Samuel O. Macauley, Milton Margai College of Education and Technology
Samuel I. Bangura, Helen Keller International, Freetown
Osman Kamara, Helen Keller International, Freetown
Annie Sesay, Sierra Leone Sickle Cell Disease Society
Cassandra Leigh, Sierra Leone Sickle Cell Disease Society
Iyamide Thomas, GT Consultancy and UK Sickle Cell Society
Maria Berghs, De Montfort University, UK
Students and staff at Sierra Leone Grammar School, Freetown Secondary School for Girls, and the Methodist Girls High School

The original UK version plus a number of translated versions can be found on the SCOOTER website: http://www.sicklecellanaemia.org/search-our-resources#social

If you have any questions about the SCOOTER project, which was part of the 2009-2012 UK Open Educational Resource Programme you can contact Vivien Rolfe (project director) via Twitter @vivienrolfe

The Educational Context in Sierra Leone

In Sierra Leone, children are legally required to attend six years of primary school and three years of junior secondary school until they are 15 years old. This consists of the basic education that each citizen is entitled to have according to the **2004 Education Act**. The 2004 Education Act stipulates that there should be no discrimination which could prevent a child in attaining this basic education. The **2007 Child's Rights Act** also states that children are entitled to basic education. An important part of school inclusiveness is recognising the importance of offering care to young people with long standing illness, particularly since a major part of childhood is spent in attending school. The duty on ensuring inclusiveness in school falls to the school authorities who must make arrangements for supporting pupils at school with medical conditions. Pupils with sickle cell disorder fall under this legislation and guidance. In a resource-poor, post-conflict, and post-Ebola country, like Sierra Leone, there are additional constraints facing children living with serious health conditions accessing not only school but also health services. The country's educational sector was badly affected by a ten year civil war (1991-2002) and the world's most serious Ebola epidemic (2014-2016). The educational sector is rebuilding but there is a dire shortage of teachers and school facilities. Similarly, the much needed supportive medical care, specialised staff, medicines and basic operations may not be accessible unless you pay for private medical resources. This means that depending on the severity of the health condition, children may also have an impairment as they progress in the school system. For this reason, when we think of inclusiveness, the **2006 United Nations Convention on the Rights for Persons with Disabilities** is also applicable and school authorities are responsible for ensuring inclusion of a child with health condition who may further have acquired or been born with an impairment.

What is Sickle Cell Disorder (SCD)?

Sickle cell disorder (SCD) is a collective name for a series of serious inherited chronic conditions that can affect all systems of the body. It is one of the most common genetic conditions in the world and 1 in 4 people in Sierra Leone is a trait carrier. If both your mother and father carry the sickle cell gene they have a one in four chance in each and every pregnancy of having sickle cell disorder. Sickle cell disorders are associated with episodes of severe pain called sickle cell painful crises. People with sickle cell disorder have a type of haemoglobin (called haemoglobin S (HbS) or sickle haemoglobin) which differs from normal adult haemoglobin (haemoglobin A or HbA). This can cause red blood cells to change shape and become blocked in the blood vessels, causing acute pain. Many systems of the body can be affected, meaning that key organs can be damaged and different symptoms can occur in many different parts of the body. The main types of sickle cell disorder are sickle cell anaemia, haemoglobin SC disease (slightly milder) and sickle beta-thalassaemia. There is a small but significant Lebanese population in Sierra Leone and so beta-thalassemia trait may also be reported.

How can the symptoms of sickle cell disorders (SCD) be prevented?

Certain factors have been identified as more likely to precipitate a painful sickle cell crisis. These include infections, cold and/or damp conditions, pollution, dehydration, strenuous exertion, stress, sudden changes in temperature, alcohol, caffeine, and smoking. Advice to people living with a sickle cell disorder on preventing crises includes keeping warm, eating healthily, taking moderate exercise, taking plenty of fluids, getting enough sleep, seeking medical advice if they have a fever, avoiding smoking and alcohol, keeping up to date with medications and vaccinations, and trying to live a stress free life.

Good Practice: Education and Awareness

The **Sierra Leonean Sickle Cell Disease Society** have two clinics in Freetown (25, Thomas Street & 86-88, Kissy Road) which can refer children with sickle cell to the specialist health services at Ola During Children's Hospital and to their dedicated nursing ward at the Connaught Hospital. They can refer people to private hospitals too. They counsel parents, caregivers and children with sickle cell about how to deal with any difficulties at school. They have produced leaflets about sickle cell disease and a special guide to sickle cell disease for teachers. They have been working closely with teachers in three schools in Freetown to ensure education, set up sickle cell school clubs to sensitize schools and create more inclusive environments for children.

Preventive measures to support people with SCD

Since people with SCD are ill-suited to hard manual work, it becomes doubly important for those with SCD to receive a good education so they can go on to support themselves in informal and formal employment. This is why encouragement to attend school and support from other students, parents, teachers and principals is very important.

Good Practice: A Gender Issue

For the **Sierra Leone Sickle Cell Disease Society**, sickle cell is a gender issue. It is of the utmost importance that girls are taught about sickle cell and that girls with sickle cell are encouraged to stay in schools. Often it is girls that will drop out of schools due to early pregnancy or because they have sickle cell. This should be discouraged and girls who are pregnant allowed to attend school. Ensuring reproductive education for boys and girls is particularly important as many leave school at 15 and schools should be encouraged to develop this. This should happen alongside education and awareness of what sickle cell is and how to live with the condition. It is often women that end up caring for children with sickle cell when they find out they are carrying or have a child with sickle cell.

***School absences*:** If schools do not have strong supportive frameworks on sickle cell disorder to reduce school absences, then studies have suggested that a pupil with SCD could miss weeks of schooling a year, most often in short absences of 2-3 days at a time. Most pupils with SCD do not feel supported by schools in catching up these absences nor are allowed to re-sit exams. This means that they might repeat the year and there is danger of them dropping out of school. Parents are also affected if a child with sickle cell has to stay at home for periods of time because this means loss of income. Sometimes a family member/sibling has to look after the child affecting their education too.

Good Practice: Exams and Assessments

Exams can cause children with sickle cell stress. Stress can be one of the triggers for a crisis. It is important that children are encouraged to prepare well in advance so exams do not cause too much stress. Discourage all night study camps for children. One school has teachers that tell the children to read ahead and prepare for exams. Children can also get stressed out if they have to miss exams. The same school ensures that children bring in medical certificates from the doctor or the hospital if they have been absent. They then ensure that they put in place provisions to allow the student to re-sit exams or assessments. The teachers do not ask any extra money to do this. This not only helps the young person with sickle cell catch up, but it does so without drawing attention to them as different from other pupils.

***Water*:** Young people with SCD need to be well hydrated to reduce the likelihood of becoming ill. If possible, have a ready supply of drinking water available. Do not restrict drinking water in class. Some schools only let children drink during the lunch break or at the school clinic if there is one. Other schools do not have any running water at all. It is important to allow children to bring water to drink between classes.

Good Practice: Ensuring Water Access and Hand Washing
Some schools still have the chlorine buckets and taps with soap and water that were present during the Ebola epidemic. They use them to ensure children have access to water and can wash their hands before they enter the school. This stops the spread of infection and allows children easy access to water.

***Sanitation facilities*:** It is important that a school has proper sanitation facilities and that access for girls to private secure facilities is present on school grounds. People with SCD cannot concentrate urine as readily. They produce large quantities of dilute urine and need to go to the toilet more often. While it is not the practice, it is important not to restrict the toilet breaks. This should be the case even when there are no proper facilities.

Tiredness: The person with SCD may experience severe anaemia. This may mean they feel tired, lethargic and unable to concentrate. They may feel tired to the point where they feel they need to sleep during the day. It is important that teachers do not mistake serious medical symptoms of SCD for laziness. Walking to school or having to fight to ensure a place on the overfull poda-podas (mini-buses) can be physically demanding for some young people with SCD. Additionally, some children may be attending school after carrying out informal work in the morning or will have to go work in the afternoon. Forced and compulsory child labour is not legally allowed in Sierra Leone, but it does occur. Teachers should talk to parents about this if they have the chance because it causes children to be tired and unable to learn. It can also lead to the dangers of a sickle cell crisis.

Good Practice: Looking After Each Other
Schools can encourage their students to look after each other when they are coming to school. Encourage children to learn to save seats for each other on the poda-podas or school buses going and coming from school. In this way a child with sickle cell will not feel different and children learn to look after each other.

Corporal Punishment: While frowned upon by outsiders, it is still the case that 'beatings' or 'floggings' are commonly used in homes and schools to discipline children. This can pose risks to a child with sickle cell in the school environment, in terms of leading to a crisis or exacerbating health complications or impairment linked to the condition. Teachers should discipline children, if they misbehave, but they can do it in another manner than beating their students.

***Physical Exercise*:** Avoid hard, physical exercise involving strenuous exertion that could precipitate a sickle cell crisis. Encourage moderate exercise. Listen to the young person who will come to know their own safe limits of physical activity and want to play with their friends. For SCD do not refuse requests if a young person asks to be excused or stop activity because of tiredness or pain. For children with SCD, cold or wet weather, or exposure of the skin to cooling wind may all be a trigger to episodes of illness. Obligatory sports and physical exercise sessions out of doors in cold and wet weather is a potent stimulant to crisis for some children. It is important to listen to the child and parent, and follow advice from their doctor about this.

Good Practice: Outings
Schools often have outings which children look forward to. Yet, young people with SCD are advised not to become cold. This may happen when playing in the rain, coming home in the rain or even swimming, for example, when coming out of the water. It is always important to listen to the views of parents and the young person about inclusion in activities such as outings. One school made an arrangement with parents to ensure that their child had a rain coat and umbrella ensuring that they could attend outings during the rainy season. They also ensured that if it was raining hard, the child could wait in the school until the rain cleared. Another school ensured that children could go swimming in water but they dried off quickly and changed into dry clothes.

Infection: Young people with SCD may have a damaged or missing spleen (the organ that helps to fight infections). Enable safe storage and dispensing of any medicines prescribed for the young person with sickle cell disorder.

Good Practice: Sick Bays and School Nurses
One school has a dedicated sick bay but they cannot access all medicines. Instead they ensure that children bring their pain medication to school and they have a nurse on site to assist them. They also have a place for children to rest in their sick bay on a small bed. If a child feels better they can return to class. If a child goes into a crisis, they have a policy that they immediately call the parents and are aware of their mobile phone numbers. Future policy could also encourage a number for ambulances to be known.

***Temperature*:** Avoid activities that require outdoor work in very hot or very cold or damp conditions such as during the rainy season. Maintain good ventilation of study areas especially in overcrowded classrooms but do not sit children with sickle cell right under fans. Allow coats to be worn in class, and permit the child with SCD to stay inside at break in cold or wet and windy weather. If the weather is very hot in the dry season, ensure children have shade to play under. If a private school has air-conditioning, ensure that it is not too cold in the classroom and the child with sickle cell is not exposed to direct draughts of cold air.

Good Practice: Ensuring Proper Ventilation and Clean Environments
Many classrooms in Sierra Leone are overcrowded. As a result, they are too hot in the dry season and may attract mosquitos in the rainy season and become humid. One school ensures that they have proper ventilation in the classroom. When it is the Harmattan and the classroom becomes cold, the teachers also ensure that children can wear their uniform coats inside so children with sickle cell can keep warm. They also ensure that the general environment of the school is kept clean and that there are no breeding areas for mosquitoes.

How does someone get sickle cell disorder (SCD)?
Sickle cell disorders and major are inherited, that is passed on through the family. They are **not** infectious diseases and **cannot** be caught like coughs/colds. Explain this to all children and teachers. Sickle cell carriers are sometimes referred to as having sickle cell trait. Carriers have a usual and an affected gene. In the case of sickle cell carriers their red blood cells contain both usual haemoglobin (adult haemoglobin, haemoglobin A) and sickle haemoglobin (haemoglobin S). Carriers are usually perfectly healthy themselves, and may not know they have trait unless they have a blood test. If someone is a carrier it cannot turn into sickle cell disorder. For example, if both partners are sickle cell carriers (haemoglobin AS), then **in each and every pregnancy** there is a one in four chance that they could have a child with sickle-cell anaemia (haemoglobin SS, the most common type of sickle cell disorder); a one in four chance of a child with normal haemoglobin (haemoglobin AA), and a one in two chance of a child who is a sickle cell carrier (haemoglobin AS).

Good Practice: Care Plan
All young people with a medical condition at school should have an individual care plan. This plan should cover as a minimum: preventive measures to keep the child well at school; arrangements for pain medication; what constitutes an emergency; teachers or school nurse that have been sensitized about sickle cell and the mobile numbers of the parents. The plan is reviewed each year and is checked against the staff the young person is likely to meet during their academic year.

All children with SCD/ thalassemia should have a form, on which is written their **care plan,** to give to the school, which should be reviewed yearly. As sickle cell conditions have numerous possible complications affecting many systems of the body, it is important, where possible, to include the doctor in making recommendations on the form.

A Care Plan for a School Child with Sickle Cell

Name: Date of Birth: School: Current Class: Condition: Date of Plan: Review Date in one year	 Photograph
PARENT/GUARDIAN/CARER CONTACTS Contact Name: Relationship: Contact mobile number: Contact Name: Relationship: Contact mobile number:	**CONTACT NUMBERS** Emergency Contact Name: Emergency Contact number: Hospital Consultant Name: Hospital Consultant Number: Specialist Nurse Name: Specialist Nurse Number:
KEYWORKER RESPONSIBLE IN SCHOOL: Name: Building/Department: Contact Number:	**DOCTOR:** Contact Name: Contact number:

PREVENTION:

Key worker to ensure that each member of school staff follows these preventive measures…….

- Unrestricted access to drinking water during class time
- Unrestricted access to use of the toilet, including during class time
- Keeping warm during Harmattan season: permitting coat in class
- Keeping cool during the dry season
- Not forcing to undertake exercise if they say they are tired or in pain

MEDICATION

Name of medication: Dosage:

Time of medication:

PAIN MANAGEMENT

The aim is to strike a balance between responding appropriately to medical emergencies and maintaining an inclusive school environment where a pupil with sickle cell disorder is not constantly sent home for episodes of minor pain. Ask the specialist sickle cell nurse or hospital consultant if there is a pain scale suitable for use in getting the young person with sickle cell disorder to say how severe the pain they are in. There are scales in which a young person is shown drawings of a series of cartoon faces ranging from happy (no pain) to sad and crying (most pain). Such a scale could be included in the individual education, health and care plan. The following scale is for illustrative purposes only and any scale used should have the approval of the young person's doctor.

PAIN SCALE

0	2	4	6	8	10
I am not in any pain	I am in a little pain but don't need my medication	I feel if I have my medication I can be in class	I feel I need to have time out but may feel better later	I feel I need to go home	I feel I need to go to hospital

OTHER PARTICULAR NEEDS/ISSUES

This section can contain information specific to the young person's individual condition (for example, information about silent strokes, leg ulcers, priapism, headaches, seizures or other possible complications of sickle cell disorder).

Stakeholders in drawing up the care plan:

Name of Person:	Signature:	Date:
Guardian/Carer:	Signature:	Date:
School Nurse:	Signature:	Date:
Sickle Cell/ Specialist Nurse:	Signature:	Date:
Teacher:	Signature:	Date:

School Staff Who Have Received Sickle Cell Awareness Session:

Name:	Date:

Space to include specific new examples of good practice developed by the school:

Medical Issues and Medical Emergencies for Sickle Cell Disorders

Acute chest syndrome: Signs include chest pain, coughing, difficulty breathing, and fever. It can appear to be similar to flu like symptoms. However, it is important to see a consultant immediately.

Aplastic crisis: This is when the bone marrow temporarily slows its production of red blood cells, usually due to infection with a virus called ParvovirusB19. This results in a severe drop in the red cell count and severe anaemia. Signs include paleness, fatigue, and rapid pulse.

Fever: Children with sickle cell disorder are at increased risk for certain bacterial infections. A fever of 101° Fahrenheit (38° Celsius) or higher, could signal an infection. Children with sickle cell disorder and fever should be seen by a consultant without delay.

Hand-foot syndrome (also called dactylitis): Painful swelling of the hands and feet, plus fever. It is most likely to occur in children under five. It is important nursery and pre-school staff are aware of this to avoid false accusations of non-accidental injury.

Painful crises: These may occur in any part of the body and may be brought on by cold or heat or dehydration. The pain may last a few hours or up to 2 weeks or even longer, and may be so severe that a child needs to be hospitalized. It is important to listen to the young person who will come to know whether the pain is mild or moderate and will pass (where schools can promote school inclusion by permitting rest and re-integration into school later that day) or whether they need to go to hospital.

Splenic sequestration crisis: The spleen becomes enlarged by trapping the sickle shaped red blood cells. This leads to fewer cells in the general circulation. Early signs include paleness, weakness, an enlarged spleen, and pain in the abdomen. It is important that nursery and pre-school staff are aware of this life-threatening event, as it is more likely in younger children.

Strokes: The higher risk is in children aged 2-10 years. Apply the FAST approach:

Facial weakness: can the person smile, or has their mouth or eye drooped?

Arm: can the young person raise both their arms above shoulder height?

Speech problems: can the person speak clearly and understand what you say?

Time: to dial the mobile phone number of the parents.

It can be difficult to differentiate the symptoms of stroke from those of a sickle crisis, where pain can result in restriction of movement.

Silent Strokes: Changes in a young person's behaviour or concentration or a sudden deterioration in the quality of their school work could be due to several reasons. In up to a fifth of young people with sickle cell disorders, small areas of brain damage are evident on a sensitive brain scan (MRI scan) resulting from impaired blood supply. It is important to liaise with the young person's medical consultant in order to investigate if such changed behaviour is owing to a silent stroke.

Priapism*:* An unwanted painful erection of the penis, unrelated to thoughts about sex. Urgent medical help should be sought if it lasts more than two hours.

Pain: SCD is an unpredictable condition, variable over time and between different people. This creates uncertainty for the young person. The painful crises can come on quite suddenly. Pain can make a person grumpy, unresponsive and uncooperative. The pain of a sickle cell crisis can be mild, moderate or severe. Since pain is such a common experience for people with SCD it is vital that the school develops a policy for supporting children when in pain. The care plan needs to be worked out individually for each child, with input from teacher, school nurse, doctor, child and parents. It is very important that the policy includes instructions about giving medicine (including who is responsible for administration of the medicine).

Medication: A key part of the care plan should include arrangements for giving medication, and agreed procedures for assessing the severity of the pain. The key is to listen to the young person. Where pain is mild or moderate a key aim should be to keep the young person in school, by combining pain medication with an opportunity for rest and time out in a safe environment so that they can return to lessons later in the day. A blanket policy on not administering drugs or on having a young person collected as an outcome of administering any medication will in effect be an exclusionary policy for the young person with a sickle cell disorder.

Good Practice: Sickle Cell in the Curriculum
One means of creating a positive school ethos is to make the curriculum relevant to the pupils. The pattern of genetic inheritance for sickle cell should be an integral part of health sciences, biology and genetics education. Currently, students study sickle cell as part of their lessons linked to biology or health sciences and only understand sickle cell as 'disease'. It should also be a part of the sexual and reproductive health education that students receive before leaving school. The UK Sickle Cell Society (http://www.sicklecellsociety.org) has produced guidance on how sickle cell can be incorporated into various key stages of the national curriculum which could be adapted to the Sierra Leonean context.

Teacher Awareness: All staff should be made aware of sickle cell. Some schools cover this using part of a teacher in-service training day. Staff should know what to do if a child has a painful crisis, how to recognize signs and symptoms of a stroke in young people with SCD, and learn to listen to a child if the child says they are feeling unwell. Ensure there are robust systems for relaying this information when the child has a substitute teacher, when they change class or when they change school. Ensure the availability of a safe shaded area or a sick bay for a pupil with SCD to recover and take time out from activities. They may be able to return to study later in the day.

Good Practice: Medical Issues
The Sierra Leone Sickle Cell Disease Society advise in their guide for teachers, that teachers contribute to the health of children by watching for symptoms of sickle cell disease. They note that if the child is tired, listless and pale, they should advise the parents or school nurse. If the child gets joint pain, they should be allowed to lie down in the sick bay and given access to plenty of water by the school nurse. Simple pain medication like paracetamol can be effective but if the child is experiencing severe pain or has a fever the parents should be contacted and they should be taken to the hospital urgently.

Challenging Discrimination**:** Ensure that SCD is discussed and answer any questions children have about sickle cell. Do make sure that other pupils are challenged on any discriminatory views. Do not use language like 'not normal' or single out children with sickle cell as 'different'. It is important that school authorities and teachers react quickly if they identify any bullying or exclusion of children with sickle cell. The **Sierra Leone Sickle Cell Disease Society** in their guide for teachers note that children can pick on other children because of the symptoms of sickle cell, such as, yellow eyes, distended bellies or ulcers on legs. Teachers should be watchful that such behavior does not happen.

Good Practice: Sickle Cell Clubs
One way to contribute to education around this issue and awareness in students is to organize sickle cell clubs in schools. Schools in Sierra Leone use these clubs to sensitize students around issues of sickle cell in society and contribute to education and awareness around the issue. Schools in Freetown like **Sierra Leone Grammar School** and **Freetown Secondary School for Girls** are leading examples of good practice in this area. The teachers are motivated to assist the students with their school clubs, have links to the Sierra Leone Sickle Cell Disease Society and are given support from the principals. Sickle cell clubs are open to any pupils to join and they organize activities linked to sickle cell and include classmates with sickle cell.

FURTHER INFORMATION:

Sierra Leone Sickle Cell Disease Society
They run two drop-in clinics located at:
25 Thomas Street and 86-88 Kissy Road, Freetown.
www.sleonesickle.org

Sickle Cell Carers Awareness Network (SCCAN)
58 Bathurst Street, Freetown
42 Kainkordu Road, Koidu City, Kono.
www.sccan.org.uk

Ola During Children's Hospital
Forah Bay Road, Freetown

Connaught Hospital
Lightfoot Boston Street, Freetown

List of Schools that had Sickle Cell Clubs in Freetown, 2017
Bishop Johnson Memorial Secondary School; St. Josephs' Secondary School for Girls; Freetown Secondary School for Girls; Sierra Leone Grammar School; Methodist Girls High School; Government Rokel Secondary School; UMC Secondary School for Girls; Richard Allen High School; Government Technical Secondary School; Sierra Leone Muslim Congress; Methodist Boys High School.

There are also private hospitals in Freetown and the main towns in the provinces that can offer basic treatment for sickle cell patients.

RESEARCH

For a link to the research evidence underpinning the production of this information, please visit:
http://www.sicklecelleducation.com.

This site includes resources for teachers including: *My Pupil has Sickle Cell Disease* [Leaflet], *My Friend has Sickle Cell Disease* [Leaflet], *What to Do if You Suspect your Pupil is having a Sickle Cell Crisis* [Poster], *Sickle Cell and Stroke* [Leaflet], *If You Teach a Child with Thalassaemia* [Leaflet]

UK SICKLE CELL VOLUNTARY GROUPS:

The UK Sickle Cell Society
http://www.sicklecellsociety.org

OTHER RESOURCES

UK National Health Sickle Cell and Thalassaemia Service Screening Programme
https://www.gov.uk/guidance/sickle-cell-and-thalassaemia-screening-programme-overview

SCOOTER Open Education Resources for Sickle Cell and Thalassaemia
http://www.sicklecellanaemia.org/sickle-cell-anaemia/sickle-cell-anaemia-open-education-project

INTERNATIONAL GOOD PRACTICE

WEST AFRICA

Nigerian educators have adapted the guide to incorporate their peer-to-peer education initiative and refer to environmental clean-up campaigns to reduce mosquitoes and malaria. The guide has subsequently been translated into Yoruba, Hausa and Igbo.

Nigerian (English, Yoruba, Hausa, Igbo versions)

http://www.sicklecellanaemia.org/open-education-resources/sickle-cell-guide-for-schools-nigerian-english-translation
http://www.sicklecellanaemia.org/open-education-resources/sickle-cell-guide-for-schools-yoruba-translation
http://www.sicklecellanaemia.org/open-education-resources/sickle-cell-guide-for-schools-nigerian-hausa-translation
http://www.sicklecellanaemia.org/open-education-resources/sickle-cell-guide-for-schools-igbo-translation

A downloadable copy of the original UK policy guide is available at:

www.sicklecelleducation.com
www.sicklecellanaemia.org

The Sierra Leone Version of this guide was produced on the basis of grant from the **Newton Fund**.

The original policy guide was first produced in 2011 on the basis of research funded by the United Kingdom **Economic and Social Research Council** (RES-000-23-1486), a research grant held by Simon Dyson, Lorraine Culley and Sue Dyson (De Montfort University); Karl Atkin (University of York) and Jack Demaine (Loughborough University).

Sierra Leone Version 1.0 **Date: 31ST March 2017**