



ARISE

African Research And Innovative  
Initiative For Sickle Cell Education

# Train-the-Trainer Workshop

## Abuja, Nigeria

### 11th – 13th September 2019

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This project has received funding from the European Union's Horizon 2020 research and innovation programme under the Marie Skłodowska-Curie grant agreement No. 824021





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# Primary Health Care

## - Initial assessment and counselling for Sickle Cell Disease

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# participants

- Community Health Extension Workers (CHEWs)
- Health Care Volunteers
- Nurses
- Doctors
- Traditional Birth Attendants (TBAs)



# Learning objectives

- Learning Objective
- 90% of babies – effective treatment of diagnosed patients at the primary health care level
- Linkages of three tiers of health care



# outline

- Introduction
- Role of PHC
- SCD related counselling and education
- SCD related assessments
- Linkages to other levels of care
- Challenges of PHC related care
- Overcoming the challenges
- Summary



# introduction

- SCD is a public health problem
- Nigeria has the largest burden of SCD world wide
- Estimated 150 – 200,000 babies been born annually
- With new born (infant) screening for SCD, number estimated to rise
- Provision of health care facilities for babies diagnosed with SCD
- Majority of population is in the rural areas, where PHCs provide most medical care for wards and villages
- **Can PHC provide the bulk of SCD care?**



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# Primary health care (PHC) definition

- Primary Health Care, or PHC, refers to "**essential health care**" that is based on **scientifically sound and socially acceptable methods** and technology, which make **universal health care accessible** to all individuals and families in a **community** (WHO)
- Essential health care
- Universally accessible and acceptable to all
- Full community participation
- Cost the community can afford





# PHC: basic functional unit of public health services

Provide accessible, acceptable and affordable healthcare with community participation to promote health, prevent illness, care for ongoing illness, and manage ongoing health problems

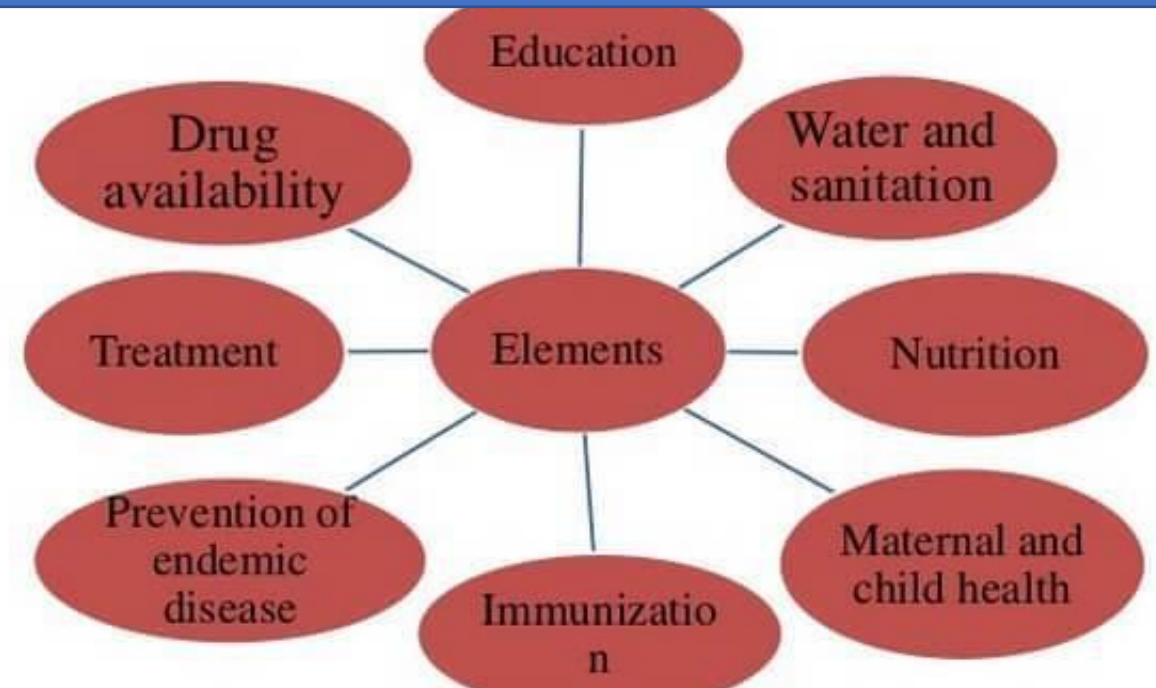
## Pillars of PHC

Community participation

Intersectoral coordination

Appropriate technology

Support materials and technology



Provided by Health care professionals – Doctors, Nurses, Midwives, Community Health Extension Workers, Community volunteers, NGOs, depending on the needs of the community, health care professionals and facilities available, proximity to other healthcare facilities and geographic location of community

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# Role of PHC

- Implementation of a community-based intervention program - comprehensive health care package for
- identification of people with SCD,
- prevent illness,
- maintain health,
- recognize early warning signs of complications,
- and institute appropriate referral mechanism to health centres where advanced medical care can be given at low cost



# Role of PHC

- Community education: parents, caregivers, and health care workers with basic health education to look after patients with SCD
- Prompt and effective referral systems for SCD and linkages to other tiers and programs of health care practice
- Community participation in care of SCD encompasses everyone – health care practitioners, traditional medical alternative practitioners e.g. TBAs, NGOs, FBOs, volunteers



# What is available in Nigeria

- 3 levels of health care – primary, secondary and tertiary
- National Primary Health Care Development agency - manage and support PHCs
- NGOs, FBOs, traditional alternative health care provision, volunteers
- One PHC/LGA No of PHC,s with variable number and level of training of staff, health care provision – well baby clinics, immunization, deliveries, simple surgeries, blood transfusions,
- Various programmes of care with variable degrees of integration - CHEWs, Midwives scheme
- Established linkages to secondary and tertiary health care facilities within geographic proximity – access and acceptability of these?



## What is available in Nigeria (2)

- Integration of programmes in health care facilities is present, but how effective are these? Midwives service scheme, under 5 care
- Availability of expertise for HIV care and use especially in referrals, transportation of samples for NBS, retention in care, community participation through volunteers etc.
- Although facilities for new born (infant) screening for SCD is available, how effective is the programme?
- SCD care is located mainly in the secondary/tertiary health care facilities
- Integration of SCD care in PHC is not standard in Nigeria, and there is inadequate/improper planning for SCD services at community level.



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- The Ouagadougou Declaration of the WHO states that, CHCM should be incorporated into health systems, making use of the primary health care (PHC) approach in order to meet rural and urban dwellers' needs





# Comprehensive health care package

- Simple easy to use interventions has been found to reduce SCD mortality to < 5% in Cotonu and < 1.5% in Nigerian setting
- **These interventions can be implemented at the home, community and PHC level**
- Early identification of SCD, the prevention, early recognition and prompt treatment of the complications
- National registry for SCD
- Prompt enrolment and retention of affected children in care programs
- Education and counselling of family, community to SCD for disease prevention, health promotion of affected
- Prompt referrals of affected persons with acute events
- Establishing linkages to other secondary or tertiary care centres for checks at diagnosis, and at least once a year (screening TCD, Hydroxyurea)



# Comprehensive care for SCD – identification

- Community awareness to SCD
- Health care provider SCD awareness – Guidelines of care, SCD policy
- Early identification of children with SCD
- **Policy on routine diagnosis of SCD** – either for Nigeria or institution
- New born or infant screening programme (NBS)
- routine genotype checks e.g. immunization clinics, well baby clinics, ANC, family screening, school entry, drivers license etc.
- Note availability of rapid screening and point of care test devices for SCD e.g. sicklescan



# Comprehensive care for SCD - services

- Parental counselling and education
- Education on the need for adequate nutrition
- Education of the need for adequate hydration
- Early identification of fever and its urgent treatment
- Early identification of a large spleen
- Use of prophylactic medications like Penicillin V, anti-malarial drugs, Folic acid and Vitamin C
- Immunization against infections - Salmonella, Hemophilus influenza type b, Pneumococcus and Hepatitis B virus infections
- Need for regular hospital follow-up.



# Comprehensive care for SCD – counselling and education

- Should be done at first contact, and preferably at each visit
- Parents, affected children, older siblings, family members, community
- Provide accurate information and use local languages for ease of understanding, verify learning and understanding of information
- Genetic and reproductive counselling – give information as to the inheritance of the disease
- Counselling to care of the child with SCD for health maintenance
- Counselling to come for clinic appointments whether child is ill or not
- Counselling of adolescents /for psychosocial issues with SCD
- Education on pathophysiology- how SCD causes complications disease



# Comprehensive care for SCD – nutritional status

Delayed growth and development, poor nutritional status and delayed puberty occur in SCD

Probably due to increased caloric requirements – frequent illness and poor feeding

Identify what foods the family eats and counsel on locally available, cost effective nutritious foods

Avoid non nutritious food and snacks

Frequent feeding with ill health, and food to prevent anaemia e.g. beans, vegetables, affordable animal protein



With adequate nutrition, children with SCD are able to achieve normal growth and development as their peers with normal haemoglobin.



# Comprehensive care for SCD – anaemia



early identification of danger signs: worsening anaemia (whitening of skin, lips, conjunctiva), easy tiredness, palpitations/feeling our heart beats, fast breathing
















# Comprehensive care for SCD – pain



**COMPARATIVE PAIN SCALE CHART (Pain Assessment Tool)**

										
0 Pain Free	1 Very Mild	2 Discomforting	3 Tolerable	4 Distressing	5 Very Distressing	6 Intense	7 Very Intense	8 Utterly Horrible	9 Excruciating Unbearable	10 Unimaginable Unspeakable
<b>No Pain</b>	<b>Minor Pain</b>			<b>Moderate Pain</b>			<b>Severe Pain</b>			
Feeling perfectly normal	Nagging, annoying, but doesn't interfere with most daily living activities. Patient able to adapt to pain psychologically and with medication or devices such as cushions.			Interferes significantly with daily living activities. Requires lifestyle changes but patient remains independent. Patient unable to adapt pain.			Disabling; unable to perform daily living activities. Unable to engage in normal activities. Patient is disabled and unable to function independently.			

Pain is a common feature of SCD both acute and chronic

Assessment and management of pain improves the outcome in affected

Educate parents and caregivers to look for pain, precipitating factors, and promptly assess and manage with simple measures like increased fluid intake and analgesics – eg paracetamol (WHO stepwise ladder), and to seek medical attention



# Comprehensive care for SCD – adequate hydration



In SCD under certain conditions (fever, dehydration, stress), red blood cells become rigid and sickle, the blood becomes thick and flows sluggishly, leading to obstruction of blood flow

This causes pain in the areas where blood flow is inadequate – vaso occlusive crisis VOC, and contributes to end organ damage

Dehydration makes the blood thicker and flow slower

Children should drink water 1 – 1.5 times the normal daily requirement, until the urine is clear amber light yellow colour

Water bottles, and drink when not thirsty

Drink frequently – before breakfast, with breakfast, before lunch, with lunch, after lunch, before play, after play, before dinner, dinner





# Comprehensive care for SCD – fever: early identification and treatment



Fever is an emergency in SCD, and associated with illness and deaths

Fever is often due to infections or malaria from poor immune system

Educate about identification of fever – thermometer or by touch and feel

What to do when there is fever – tepid sponge, give paracetamol and go to hospital at once or asap  
Patent medicine stores, chemists, self medications, old medicines at home etc. – not to be done

What to do when PHC is closed should be clear – establish linkages to other centers



# Comprehensive care for SCD – early identification of large spleen

Splenic sequestration is a complication of SCD that is a true life threatening emergency  
Pooling of blood in the spleen makes it to become large rapidly, causing a worsening of anaemia, shock and death if untreated

Requires urgent blood transfusion

Teach parents to feel for the spleen, know its size, and go to hospital once a change is noted for evaluation, weather the child is ill or not, at any time of the day

Note: scarification marks on abdomen



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# Comprehensive care for SCD – immunizations

## Nigerian National Immunization Schedule for Children

MINIMUM AGE OF CHILD	TYPE OF VACCINE
At birth	<ul style="list-style-type: none"> <li>• BCG</li> <li>• Oral Polio Vaccine (OPV)0</li> <li>• Hep B birth</li> </ul>
6 weeks	<ul style="list-style-type: none"> <li>• Oral Polio Vaccine (OPV) 1</li> <li>• Pentavalent (DPT, Hep B and Hib) 1</li> <li>• Pnemococcal Conjugate Vaccine (PCV) 1</li> </ul>
10 weeks of age	<ul style="list-style-type: none"> <li>• Oral Polio Vaccine (OPV) 2</li> <li>• Pentavalent (DPT, Hep B and Hib) 2</li> <li>• Pnemococcal Conjugate Vaccine (PCV) 2</li> </ul>
14 weeks of age	<ul style="list-style-type: none"> <li>• Oral Polio Vaccine (OPV) 3</li> <li>• Pentavalent (DPT, Hep B and Hib) 3</li> <li>• Pnemococcal Conjugate Vaccine (PCV) 3</li> <li>• Inactivated Polio Vaccine (IPV)</li> </ul>
6 months of age	<ul style="list-style-type: none"> <li>• Vitamin A 1<sup>st</sup> dose</li> </ul>
9 months of age	<ul style="list-style-type: none"> <li>• Measles</li> <li>• Yellow Fever</li> </ul>

\*BCG should be given preferably at birth (within 2 weeks) but can be given up to 11 months of age

\*\*OPV0 must be given before the age of two weeks

\*\*\*Hep B birth to be given within 24 hours after birth preferably, but can be given up to 14 days of birth

***Vaccinated communities; Healthy communities!***

Visit any government health center to complete  
your Child's immunization NOW



Infections are a common cause of deaths in SCD

Immunizations are available to prevent specific infections in SCD, particularly against Pneumococcus, Haemophilus

Influenza and Salmonella typhi

Educate on the importance of immunizations according to NPI and additional vaccines to be paid for by the parents as required

Salmonella vaccine and booster doses of Pneumococcal vaccines are not part of NPI



# Comprehensive care for SCD – drug prophylaxis to prevent infections and promote health

Folic Acid 5mg daily – for chronic anaemia



Vitamin C – anti oxidant because of the oxidant stress imposed by the red cell hemolysis

Malaria prophylaxis – association of VOC, Hyper haemolytic crisis, megaloblastic crisis, worsening anaemia, deaths with SCD. Reduces VOC, hospital admission and blood transfusions, No ideal malaria prophylaxis but guidelines recommend proguanil, along with insecticide treated bed nets and environmental control in our malaria endemic country

Penicillin V – to prevent pneumococcal infection is given along with pneumococcal vaccine





# Comprehensive care for SCD – follow up

- Often, people present when they are sick and not for routine care
- Educate on the need for regular follow up by health care professionals to maintain good health – promote health, prevention, early identification and prompt management of complications.
- Where – most feasible place for the best interest of the child – PHC, hospital, home
- Encourage parents to keep appointments for scheduled follow up
- Follow up monthly x 6, then 3 monthly cost – free
- Educate on where to go with problems during times when PHC is closed is very important
- PHC to have linkages where emergency care can be provided, as well as long term follow on care



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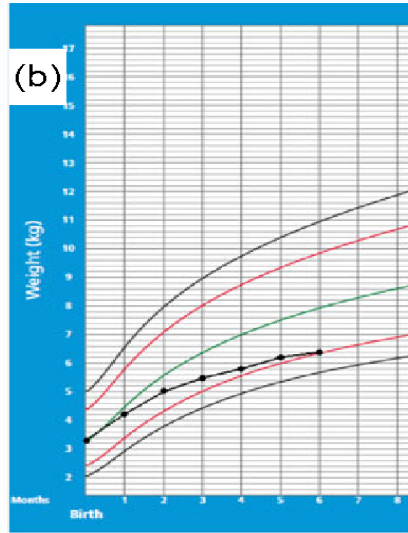
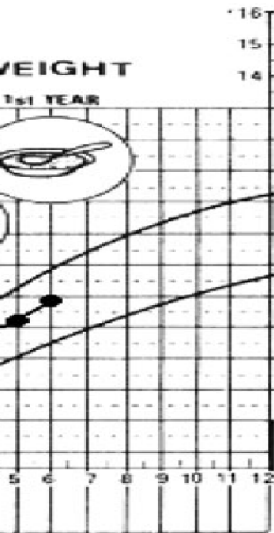


# Comprehensive care for SCD – clinic assessments

- After identification of child with SCD, at risk family, counselling and education
- Extensive history
- Check immunization status
- Check nutritional status - Height and weight
- Ask about pain
- Physical examination - pallor, jaundice, dehydration, spleen, liver, chest, heart sounds, CNS
- Laboratory assessments - Hb, PCV, Malaria Parasites, urine analysis  
POC testing available

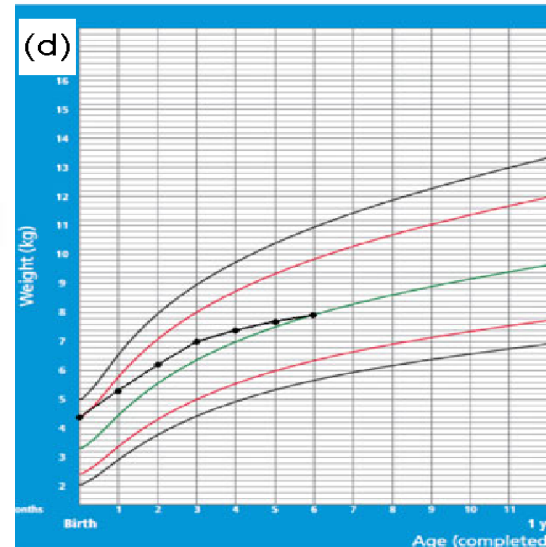
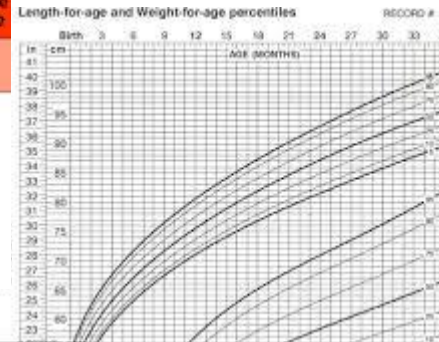


# Comprehensive care for SCD – assessment charts



## COMPARATIVE PAIN SCALE CHART (Pain Assessment Tool)

0	1	2	3	4	5	6	7	8	9	10
Pain Free	Very Mild	Discomforting	Tolerable	Distressing	Very Distressing	Intense	Very Intense	Utterly Horrible	Excruciating Unbearable	Unimaginable Unspeakable
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NATIONAL PRIMARY HEALTH CARE DEVELOPMENT AGENCY  
**CHILD HEALTH CARD**

ENTER CARD NUMBER HERE: \_\_\_\_\_

INFORMATION ABOUT CHILD

Child's Name: \_\_\_\_\_ Child's Sex (M/F): \_\_\_\_\_  
 Date of Birth (day/month/year): \_\_\_\_\_  
 Weight at Birth (in kg): \_\_\_\_\_

CHILD'S RESIDENTIAL ADDRESS

House Number: \_\_\_\_\_  
 Village/Settlement: \_\_\_\_\_  
 Town/City: \_\_\_\_\_ Ward: \_\_\_\_\_  
 LGA: \_\_\_\_\_ State: \_\_\_\_\_

Mother's Name: \_\_\_\_\_  
 Mother's GSM No: \_\_\_\_\_  
 Father's Name: \_\_\_\_\_  
 Father's GSM No: \_\_\_\_\_

MOTHER'S OTHER CHILDREN

Year of Birth	Sex	State of health

Ask the mother about these reasons for giving the child Extra Care and make a circle round the right answer:

- Did the baby weigh less than 2.5kg at birth? YES/NO
- Is the baby a twin? YES/NO
- Is the baby bottle fed? YES/NO
- Does the mother need more family support? YES/NO

NOTE: If the child has had any adverse or negative reactions to vaccines (NRT) or any other special contraindications, note symptoms and vaccine responsible, if any.

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# Comprehensive care for SCD – treatments at PHC

- **Simple effective treatments at PHC level, depending on the capability** for health promotion, prevention of illness, prompt recognition of early warning signs of illhealth, treatment of same, and early referrals as required
- Pain management at home and in hospital
- Rehydration – oral, parenteral
- Malaria treatment and simple infections
- Monitoring of blood levels
- Utilization of referral systems for more difficult situations e.g. stroke, need for EBT etc.



# Comprehensive care for SCD – treatments at PHC

- Identification of fever determining source of fever
- Treatments for malaria
- Treatments of other common infections
- Pain management
- Rehydration
- Identification of need for blood transfusion, and prompt effective referral or linkages to provide same



# PHC care in Nigeria

- [Trans R Soc Trop Med Hyg.](#) 2018 Feb 1;112(2):81-87. doi: 10.1093/trstmh/try025.
- **Sickle cell disease in southwestern Nigeria: assessment of knowledge of primary health care workers and available facilities.**
- [Adegoke SA](#)<sup>1</sup>, [Akinlosotu MA](#)<sup>2</sup>, [Adediji OB](#)<sup>3</sup>, [Oyelami OA](#)<sup>1</sup> et al
- **RESULTS:** The majority of CHWs (167/182 [91.8%]) knew that SCD is an inheritable blood disorder. However, only 32.4% and 26.4% knew that SCD can be diagnosed in the prenatal and neonatal periods, respectively. Also 37.4%, 49.5% and 67.6% knew about the role of chemoprophylaxis (folic acid/penicillin), adequate fluids and malaria prevention, respectively, in SCD care. Overall, 37.9% had good knowledge on the nature and care of the disease. Just 2/46 (4.3%) PHC centres treat patients with SCD. SCD-targeted nutritional counselling and referral to secondary/tertiary hospitals were poor and unorganized. No centre offered SCD screening, home visits or recordkeeping.



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# Linkages to other levels of health care

- Are required for different reasons: as part of comprehensive care and for control of and management of SCD
- Identification of secondary or tertiary facility, accessibility geographic location and cost effectiveness, and logistics for: follow-up visits, emergency visits, parental education, and management of acute events.
- Could include TCD screening for primary stroke prevention, initiation of hydroxyurea use, eye, orthopaedic, chest screening etc
- Frequency is variable depending on the need eg yearly, 6 monthly
- Linkages to other support organisations eg sickle cell clubs, parent groups, NGOs TBAs etc



# Linkages to other levels of health care

- SCD is a non communicable disease of public health interest
- WHO has set targets for the control and management of SCD
- Effective interventions should be integrated into existing health systems, the best examples linking PHC facilities to specialized sickle cell disease centres in regional and tertiary healthcare institutions.
- **To achieve these, there should be linkages with already existing health programs and infrastructure**
- New born screening and comprehensive health care linkages 6 MDG sickle cell centers and HPLC machines in 2012
- HIV care structure, Midwives service scheme, integrated management of childhood illness, etc



# Linkages to other levels of health care

linkages	Resources required	Sources of support	How to achieve it
Newborn screening (NBS)	<p>Champion NBS as a public health service</p> <p>Build NBS programs on existing maternal and newborn programs Consider cost and logistic challenges in choosing testing methods</p> <p>Public awareness campaigns about NBS and SCD</p>	<p>Physical resources: clinics, laboratories/equipment and reagents, mobile units, research/clinical trials infrastructure<sup>9</sup></p> <p>Network of NBS across countries negotiate laboratory reagent costs as a block with manufacturers.</p> <p>Human resources: doctors, nurses, social workers, laboratory technologists, genetic counselors, data managers, and so on<sup>25</sup></p>	<p>Government health institutions, charitable clinics, north-south and south-south partnerships with foreign universities and hospitals; other sources: private sector, NGOs, and philanthropic organizations<sup>25</sup></p>





# Linkages to other levels of health care

<p>Malaria and bacterial prophylaxis</p>	<p>Tie in SCD with HIV (and other transfusion-transmitted diseases); immunization; and malaria programs<sup>9</sup>Maintain GAVI partnership for access to pneumococcal and <i>Hib</i> vaccines in primary immunization programs</p>	<p>Financial Strengthening of public health services—immunizations and malaria control programs</p>	<p>Government—Ministry of Health, private sector, nongovernmental, and other philanthropic organizations (eg, Gates Foundation)<sup>25</sup></p>
<p>Advocacy</p>	<p>Community fund-raising events (eg, bake sale, cultural events)<sup>9</sup></p>	<p>Community resources</p>	<p>Donations by charity groups; empowering parents and spouses of SCD patients<sup>9</sup></p>
	<p>Engage “first ladies” or government officials and celebrities who have family members with disease; hire lobbyists<sup>9</sup></p>	<p>Government and nongovernmental resources</p>	<p>Health Ministries, parent and advocacy groups, celebrities, lobbyists, and other NGOs<sup>2</sup></p>

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# Challenges of PHC related care

- Lack of provision of universal health care for all at all levels of health care
- Inadequate number of PHC with capacity to manage SCD
- Inadequate staff trained on SCD management in equipped PHC
- Inadequate community involvement between stakeholders of SCD care
- Not working together of stakeholders in the community
- Policy on SCD management in community?



# Challenges of PHC related care

- What is the ideal model of care for SCD in the community
- Lack of identification of SCD at PHC level – no or inadequate NBS and Hb electrophoresis
- Lack of research to identify our problems with SCD
- Burden of care for management – who pays for care?
- Lack of functional structured referral system
- Inadequate integration of specific interventions at PHC level



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# Overcoming the challenges

- Human: training and education of health personnel
- Technical (nonhuman): equipment and supplies for laboratories, medical care, and data management
- Educational and advocacy: establish sustained training and learning programs for health workers as well as creating awareness for the public
- Political will: use of support groups—both parent and patient, advocacy groups, and national representatives to attract governments' consideration of SCD as a public health priority
- Logistics: Formal referral systems and linkages
- Research into SCD



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This project has received funding from the European Union's Horizon 2020 research and innovation programme under the Marie Skłodowska-Curie grant agreement No. 824021