



A MEMBERSHIP ORGANISATION  
FIGHTING CANCER TOGETHER

# Childhood cancer 'Signs and Symptoms' campaign

Compilation of campaign materials



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In partnership with



# 1. Introduction to the campaign

A joint campaign of the Union for International Cancer Control (UICC) in partnership with Childhood Cancer International (CCI) and the International Society of Paediatric Oncology (SIOP)

## Why we developed this campaign

There are many myths and misconceptions about childhood cancer. Primary among these, is the notion that children do not get cancer. Or, that if a child is diagnosed with cancer, the child will inevitably die. Neither of these perceptions about childhood cancer is true.

While relatively rare compared with the burden of cancer in adults, childhood cancer is an important cause of child mortality. In high-income countries and a growing number of middle-income countries, childhood cancer is now a leading cause of deaths in children and adolescents.

Worldwide, approximately 300,000 cancers are diagnosed each year in those younger than 19 years of age. It is estimated that approximately 80,000 children will die of cancer each year around the world. These estimates are considered by experts as gross underestimates given that 80% of childhood cancer occurs in low- and middle-income countries (LMICs) where there are no or limited childhood cancer registries.

Over the last decades, there have been remarkable advances in the treatment of childhood cancer. For children diagnosed with cancer in high-income countries, approximately 80% survive five years or more after the diagnosis of cancer. However, in many LMICs, survival rates are drastically lower, frequently not reaching more than 30% in a number of settings and, in some countries, falling below 10%. Unfortunately, for many children, particularly in LMIC settings, cancer is often detected at an advanced stage and too late for effective treatment.

An important contributor to the problem of late diagnosis and treatment is that knowledge and awareness of childhood cancer is low, even among health professionals. Early warning signs of childhood cancer are sometimes confused with other, more common childhood illnesses.

Consequently, the Union for International Cancer Control (UICC) in partnership with Childhood Cancer International (CCI) and the International Society of Paediatric Oncology (SIOP) developed a campaign to facilitate and assist early detection of childhood cancer. This was known as the "Signs and Symptoms Campaign". This intended to raise awareness on the early warning signs of childhood cancer so that children with suspected malignancies can be referred for diagnosis and treatment as early as possible.

## About the campaign

The Signs and Symptoms campaign was launched on International Childhood Cancer Day (ICCD) in 2014 by the Union for International Cancer Control (UICC), the International Society of Paediatric Oncology (SIOP) and Childhood Cancer International (CCI).

The goal of the campaign was to increase knowledge and awareness of childhood cancer signs and symptoms, especially among health workers and encourage prompt referrals to appropriate health facilities for timely testing, diagnosis and treatment.

The Signs and Symptoms campaign was designed as a three-year project with different materials produced each year so as to develop a suite of learning, training and coaching activities. The “Kick off” campaign materials included a poster and pocket card, using icons/visuals to spotlight key early warning signs of common childhood cancers and common differential diagnoses. CCI translated the posters into 70 local languages and dialects which were then adapted for use in different countries and settings.

In the second year, to deepen understanding and recognition of early warning signs for 6 of the most common types of childhood cancer, the campaign released ‘talking head videos’. These were narrated by doctors, a nurse, a cancer survivor and a parent to contribute to increased early diagnosis by primary health care professionals or timely referrals by community volunteer health workers.

The final year activity of the campaign consolidated the learnings and insights from the campaign through a webinar series from different countries and regions that had extensively used and promoted the materials.

The following document compiles these materials into one document for easy referral. The poster, pocket card, talking head videos, presentations, and recorded webinars can be integrated in part or as a whole package into learning and training activities on childhood cancer and child health more broadly.

## Key challenges

Common challenges that the campaign seeks to address include:



## Why a focus on early detection is important

Early detection of childhood cancer is crucial to improved survivorship and better health outcomes for children/adolescents with cancer. In addition to the potential for improving outcomes, early detection and prompt referral of suspected cases can provide more timely access to treatment and care, including pain relief and symptom management as well as counselling and support services for children/adolescents with cancer, their siblings, parents and family members.

For the most part, children/adolescents with cancer who receive early diagnosis and are in early stages of their cancer, also require lower intensity treatment. Thus, early detection of childhood cancer can result in cost savings for families and health systems, as well as a lower burden of short- and long-term toxicity.

From a psychosocial standpoint, prolonged times to diagnosis may also result in unnecessary guilt felt by parents and caregivers as well as possible decreased trust in healthcare providers and systems.



## 2. Signs and symptoms poster and pocket card

The campaign has produced visually compelling and informative resources that can be used by primary healthcare providers, particularly those working in the area of childhood cancer and child health.

### The poster

This resource pictorializes the 9 key signs and symptoms of childhood cancer that are oftentimes associated with childhood cancer and may be mentioned by parents and caregivers to health workers, often in the context of routine child health check-ups or visits to primary health care facilities. The target audience includes non-paediatric specialists, particularly primary health doctors, nurses and health volunteers. These posters were designed to be displayed in primary health care clinics [PHC]/service facilities, specialty centres for children, general hospitals and other community based health facilities. The poster was designed in both A2 and A3 formats and are in colour. As colour printers are often not available, they have also been designed to work well in black and white.



## The pocket card

This resource includes a smaller version of the 'Signs and Symptoms poster' on one side, and on the reverse, a 'Table of common differential diagnoses'. It is designed to be an easy to refer to card that can fit into doctors' or nurses' pockets.

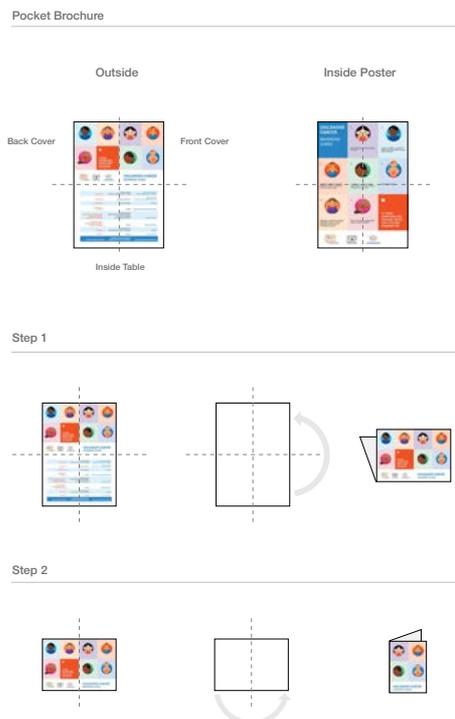
There are two possible formats:

1. A6 recto-verso which can be printed professionally.
2. A4 format, which works as a 'DIY print-out' to make into A6. This is because in many low-resource settings they are likely to only have access to basic printers. Therefore, if the pocket card is printed on A4 and folded, it can still be used in the same way.

## Table of common differential diagnosis

PRESENTING SIGNS OR SYMPTOMS	COMMON DIFFERENTIAL DIAGNOSIS (NON MALIGNANT CONDITIONS)	SUSPECTED CANCER DISEASE
Low blood counts	Infection	① Leukaemia
Bleeding	Coagulation disorders, platelet disorders, bone marrow failure	① Leukaemia
Lymph node swelling	Infection	① Burkitt-Lymphoma (BL), Non-Hodgkin Lymphoma (NHL), Hodgkin Lymphoma
Abdominal swelling	Nutrition disorder, kidney cyst, constipation, ovarian cyst, hepatosplenomegaly, haemoglobinopathy, Kidney tuberculosis	① Wilms tumour, ovarian tumour, BL & other NHL, bladder rhabdomyosarcoma, neuroblastoma.
Mediastinal mass with shortness of breath	Infection	① Lymphoma Neuroblastoma
White pupil	Congenital cataract	① Retinoblastoma
Headache, morning vomiting, ataxia, impaired vision, paresis	Migraine, sinusitis, meningitis if associated with fever (infection)	① Brain tumour
Bone pain, swelling of arm or leg without trauma or infection	Bone cyst, osteomyelitis	① Bone tumour

## How to format an A4 print into an A6 pocket card



## 3. Expert film scripts

In scaling up the campaign, the campaign partners developed a series of expert ‘talking head’ films that focus on five of the most common childhood cancer diseases globally.

The film series includes leukaemia, lymphoma, brain tumour, bone tumour and retinoblastoma. The films are narrated by doctors, a nurse, a parent and a cancer survivor and outline the history of the cancer, its signs and symptoms, key questions to be asked, examination steps and take home messages.

The following are the scripts of the expert films. These can be used as case studies in training sessions on childhood cancer or as trigger films prior to more lengthy presentations and discussions. They also help to concretize how to approach these cases.

### Lymphoma



#### Introduction

I am a doctor in Mbingo hospital, one of the Cameroon Baptist Hospitals in the North West of Cameroon and in charge of treating children with abnormal growths. Today, I want to tell you about a little boy, named Ababa, who is 8 years old.

#### History

Ababa lives in a very small town far from the hospital. He developed a growth in the cheek of his face, for which his mother took him to see the traditional healer. [Early Warning Sign: abnormal growth in the face/neck]. The traditional healer gave him “muti”, which is medicine made from herbs. The growth increased in size and his teeth became loose in his mouth. He also lost weight and ate less. [Early Warning Sign: weight loss]. He was also tired and did not want to play soccer with the other kids anymore [Early Warning Sign: fatigue]. Ababa developed a fever and Ababa’s mother took him to the nearest health clinic, where Ababa got his immunisations as a small boy [Early Warning Sign: fever]. The nurse saw him and gave him antibiotics, and told him to brush his teeth more often as she thought that dirty teeth had caused the growth. When the growth increased in size, Ababa’s mother asked help from the local priest, who advised her to go to the Cameroon Baptist Hospital in Mbingo, where there were many doctors who could do more in-depth examinations than the clinic nurse. Ababa’s mother could not bring Ababa immediately to Mbingo hospital, since the taxi fee was 500 Cameroonian Francs and she first had to raise the money for the transport costs by selling her chickens and borrowing from her brothers. It took her 6 weeks to raise the taxi fee. She went to Mbingo hospital 4 months after the start of the growth in Ababa’s cheek. By now Ababa had lost a lot of weight, often had daily fevers, had a huge mass in his face and neck and did not play at all [Early Warning Signs: fatigue, fever, weight loss, abnormal growth].

## Key questions

When I saw Ababa I asked the following questions:

- When did Ababa's growth start?
- Has he lost weight?
- Is he still eating well?
- Does he still play with his friends and what type of games does he play?
- Is he more tired than normal?
- Does he have fever?

## Examination steps

On examination, I found that there was a huge mass in Ababa's right jaw measuring 8 by 8 cm. [Examine all the lymph nodes in the neck, under the arm pits, in the groin]. The lymph nodes were also enlarged under the jaw and in his neck. I also examined his abdomen and found a large liver and spleen. [Examination of the abdomen with an enlarged liver and spleen]. I explained to his mother that we needed to take a biopsy and test his blood. Whilst his blood test came back as normal, a biopsy of the mass in the right jaw confirmed that it was Burkitt lymphoma, a childhood cancer of the lymph nodes.

We also did a lumbar puncture, which is a needle in the back, between the vertebrae or bones of the spine to get cerebro-spinal fluid, which is the fluid circulating around the brain. Sometimes this disease can spread into the cerebro-spinal fluid and this can mean more intensive treatment for a longer period. Unfortunately for Ababa the fluid was abnormal. He had to get very intensive therapy because of this and his treatment took 9 months. It was very difficult for Ababa's mother because she had to borrow a lot of money to come regularly for his treatment. Fortunately, the treatment itself was sponsored by a UK based trust so Ababa's mother did not have to pay medical costs in addition to transport costs. Ababa has survived but his treatment would have been shorter with less travel expenses for his many trips to the hospital if Ababa had been immediately diagnosed with his Burkitt lymphoma.

## Take-home messages

- If parents report abnormal lumps or growths, these should be immediately investigated for childhood cancer. These growths can be anywhere in the body.
- Information materials about early warning signs of childhood cancer need to be displayed in doctors' consulting rooms, hospitals and primary care clinics so that health staff and parents can be reminded of the warning signs of childhood cancer.
- If doctors or nurses are unsure about what is wrong with the patient they should consult a specialist or refer to a large hospital with many specialists to assist them with the diagnosis.

## Leukaemia



### Introduction

My daughter is a survivor of Acute Lymphoblastic Leukaemia and who was initially misdiagnosed as a 2-year old. She is now an adult, yet despite the fact that leukaemia is the most common cancer amongst children, there are many cases where it is still misdiagnosed. Through my daughter's experience, I came to be a part of Childhood Cancer

International and have since met many families who went through the same experience as I did. It was through CCI that I met the daughter of one of our parents who is also the survivor of ALL and who was also initially misdiagnosed. Today I will present her story to illustrate how easily this can happen.

### History

Jannah grew up as a normal, happy child reaching all her childhood milestones on queue and was always very active and healthy and only visited the doctor for regular inoculations and check-ups. This all started changing at around 19 months in the summer when some days she was less energetic and did not want to play, but her parents put this down to a growth spurt. [Early Warning Sign: unexplained fatigue]. They were not concerned at all but became more worried when on some days she did not want to walk or just walked a bit and then sat down. But as she was happy swimming in the pool they brushed this aside as Jannah being temperamental. After a couple of days, she started to limp and so

they took her to the doctor. This should have been the second red flag. [Early Warning Sign: bone or joint pain]. The doctor assured them that it was probably a thorn that she had stepped on and she would soon get better.

A week went by and she seemed better and started walking normally again. A short while later she developed a sore throat with a cough and fever. They took her to the doctor, who gave her antibiotics. Another week passed by, but the fever did not go away and she felt unwell, ate only a little and did not want to play [Early Warning Sign: fever and infection not getting better]. Later she developed little red spots on her face and arms and had some bruising. This all looked very strange so they once again took her to the doctor. She also complained of shoulder pain when they lifted her arms to dress her. [Early Warning Sign: Petechiae, which are tiny red spots or lines in the skin due to low platelets]. This time the family doctor put it down to a reaction from the sunscreen they were applying and told them to stop using that particular brand. He explained the bruising as caused during play with her older sister and told them they were overly concerned parents. Later her stomach looked swollen so they took her to the doctor again [Early Warning Sign: enlarged liver and/or spleen]. He told them that she was constipated and gave them medicine for this and told them that the spots still present would probably take a while to disappear and that they should stop worrying.

After another week, she started limping again and was reluctant to walk at all – their family doctor was now concerned and thought it may be a bone defect and so referred them to an orthopaedic specialist for further tests.

### Key questions asked by doctor/nurse

When the specialist saw Jennah he asked the following questions:

- When did Jennah start limping?
- Does she seem more tired than normal?
- When did the red spots appear and did they go away?
- For how long have you noticed that her stomach was swollen?
- When did you first notice a fever?

### Examination steps

During the examination, he manipulated her hips causing her to cry, examined her lymph glands, palpated her stomach and examined the red spots. He immediately arranged for Jennah to see a paediatrician despite it being seven o'clock at night. The paediatrician asked the same questions when he examined Jennah and then sent the parents directly to hospital for blood tests. The next morning, she was diagnosed with cancer. Jennah was then admitted to a paediatric oncology ward where they checked her bone marrow and a lumbar puncture was performed to detect the presence of leukaemia cells to confirm the type of cancer and its severity.

Jannah fortunately survived but could have been diagnosed much earlier if the doctor had been aware of the early signs of childhood cancer.

### Take-home messages

- Family doctors in their life-time will see very few cases of childhood cancer and so it is often confused with other ailments that have similar signs.
- Watch out for a combination of the symptoms, one on its own could be some other ailment, but a combination of symptoms presenting at the same time is a serious warning.
- If the symptoms do not clear watch out for additional signs of childhood cancer.
- If unsure, do not delay but ask for additional tests to be done or refer the patient to a specialist.
- Have easily accessible information in your consulting room so that you can be reminded of the symptoms of childhood cancer

## Bone cancer



### Introduction

My name is Zuzana and I am an osteosarcoma, bone tumour survivor. Although bone tumours are one of the most common cancers amongst teenagers it took quite a long time for me to get correctly diagnosed.

### History

When I was 16 one day on my way home I suddenly felt an acute, stabbing pain in the bone of my left lower leg that was so sore that I could not take the next step.

I remember like it was yesterday, I had to wait a couple of minutes before the pain subsided and just stood on the steps not knowing what to do as I could not put any pressure on my left leg and could not get home. After a while the pain subsided. [Early Warning Sign: limb or bone pain without reason] When I got home and told my family what had happened they asked me where the pain was. My simple answer was “it feels like it is in my bone”. They did not believe me and told me “a bone CANNOT hurt!”

After a few days, the continuous strange feeling in my leg bone disappeared completely. By the time I managed to get an appointment with an orthopaedist around 2 weeks later I felt no discomfort anymore. Despite this the specialist prescribed a diagnostic test called a scintigraphy to be done. The results showed slightly higher activity in the region where I had felt the pain. They asked me to come back for an annual check-up.

My orthopaedist at home didn't take any of it seriously and reassured me that my pain had been caused by a slight difference in the length of my legs and prescribed orthopaedic shoe inserts. Like all of us do, I trusted him and totally forgot to go for my annual check-ups as I no longer felt any pain. Then suddenly two and a half years later the pain was back for no obvious reason at all. [Early Warning Sign: repeated limb or bone pain without any reason].

Initially I only felt pain when I carried something heavy, but later I also felt pain when lying on my bed doing nothing. The GPs and also specialists I consulted could not reach a diagnosis as they could not see anything on the X-ray that was taken of my leg.

A few days later along with the pain in my leg, I noticed swelling of my lower leg in the region of my knee [Early Warning Sign: swelling of the region without trauma or signs of infection] and my orthopaedist again tried to assure me that it might be “water on the knee” due to my excessive sports activity and that I should not worry.

The swelling got worse and the pain intensified so much so that it no longer responded to the pain killers I was taking. I started running a fever on most days. [Early Warning Sign: fever in combination with swelling and bone pain without reason], and was limping but there was still nothing to observe on the X-rays or on the ultrasonic images. Finally my father insisted that I see a specialist in a large tertiary university hospital located in the city, where they decided to do a MRI. The results indicated a tumour.

After that everything went pretty fast. I had a biopsy to confirm the diagnosis and to determine the kind/type of tumour I had. Finally, I was told I had osteosarcoma – bone cancer!

After a few weeks all the results came in and within a few days I had started my chemotherapy at a children's hospital. Fortunately, the tumour had not spread and I was able to finish my intensive therapy after 14 exhausting months.

### Key questions asked by doctor/nurse

The specialist asked me the following questions:

- Have you hurt yourself?
- Are you an athlete or a sporty person?
- When did you first feel pain in your leg?
- For how long have you been feeling constant pain?
- Can you explain what kind of pain it is?
- What tests have you had to investigate the pain?
- When did the swelling start?

- How frequently do you get fever and how high is it?
- Does pain medication relieve the pain? If yes, for how long?

## Examination steps

The normal examination procedure is to do an X-ray of the bone, which often shows no significant results. The pain persisted, therefore he proposed an MRI as these results are more reliable when suspecting a bone tumours as you can more easily see if something is wrong. A biopsy is the only way to make sure.

## Take-home messages

- Adolescents could have a bone tumour. It is important to listen to them and consider all possibilities including cancer
- Pain in the bone is possible. Even if there is nothing to be seen on X-ray, it doesn't mean that there is nothing going on!
- Whenever there is pain and it is not responding to pain medications, please see a specialist.
- Do not ignore any kind of swelling anywhere in the body.
- In children and adolescents, early diagnosis of cancer leads to effective treatment and therefore better prognosis, which leads to less late effects.

## Brain cancer



### Introduction

I am a doctor at Max Hospital in New Delhi, India and treat children with abnormal lumps in their body. One of my patients is a 4-year-old boy called Shaurya.

### History

Shaurya is an only child and lives in New Delhi. He was attending nursery, had received all his vaccinations and had previously been well, achieving all his normal growth and developmental milestones. Around 2 months before coming to see me, he started complaining of a headache in the front of his head. [Early Warning Sign: **Hedaches in a young child**]. He complained of disturbed sleep, often waking at night because of headaches and irritability in the mornings. [Early Warning Sign: **Persistent headaches that wake a child from sleep or that occur on waking**].

Initial assessment by his paediatrician included a normal neurological examination and did not reveal any clues. Suggestions for better sleep hygiene were given alongside a prescription of paracetamol. These did not relieve his headaches. Shortly after, he began to vomit upon waking, although he did not appear to be nauseated. [Early Warning Sign: **Persistent vomiting, particularly on waking**].

A week before his diagnosis, his mother noticed that he was walking unsteadily, and that his head was tilted to one side. [Early Warning Sign: **abnormal balance and head position**].

She got really worried and took him back to her paediatrician who ordered a CT scan. This was two months after his first symptoms. The CT revealed a tumour in the back of the brain. He was then urgently referred to my hospital.

### Key Questions asked by doctor/nurse:

When I saw Shaurya I asked his mother the following questions:

- How long has Shaurya had the headaches?
- At what time of the day did he get the headaches?
- Do the headaches wake him up?
- Does he have nausea and/or vomiting with the headaches?
- Does he have any abnormal eye movements or are there any problems with his vision?
- Is he increasingly weak and clumsy?
- Has there been a change in his behaviour and activity levels at home and/or at his nursery?
- Has he had any abnormal movements, fits or unresponsive episodes?

## Examination steps

On examination, I found Shaurya to be lethargic but aware of his surroundings. His head was tilted to one side and his co-ordination was abnormal. His vision was normal but the examination of the back of the eye revealed that the pressure in his brain was higher than normal. He had an MRI brain scan under sedation which confirmed the location and size of the tumour as well as the increased pressure in the brain. He was promptly seen by our neurosurgeons and subsequently had a successful surgery to remove the tumour and relieve the pressure. Further treatment was planned after the pathology report was available. The family received timely information, counselling and support throughout the process.

## Take-home messages

- Brain tumours are the second most common childhood cancer.
- Sadly, diagnosis is often delayed because not all brain cancers have easily recognizable signs. Some signs are gradual in onset, or are similar to those that occur with other common childhood conditions.
- The signs and symptoms of brain tumours are varied and determined by the part of the brain affected, the developmental stage and ability of the child or young person, and whether or not intracranial pressure is raised.
- Routine tests may also be normal. A normal neurological exam does not exclude a brain tumour.
- Persistence or recurrence of symptoms, presence of more than one symptom or progression of any symptoms, abnormalities or changes, should raise the alarm to immediately refer and call in specialists.
- It is also important that primary care physicians and general paediatricians know the signs and symptoms which raise the possibility of a brain tumour in a child and investigate further through CT or MRI brain scan and/or link to a referral centre in a timely manner.
- Early detection of brain tumours and timely treatment improves treatment outcomes.

## Retinoblastoma



### Introduction

My name is Rehana, and I am a nurse working in the children's cancer hospital in Karachi. I want to tell you about Fatima, a patient I am looking after at the moment. She is just 2 years old, and a lovely little girl.

I first met Fatima when she came with her mother to our hospital a month ago with a suspected eye cancer, called Retinoblastoma. She had been referred to us by the community health worker in Pasni, in Gwadar district in Pakistan.

### History

Fatima's family told me that they first became worried when she developed a squint; what they called a 'lazy eye' [Early Warning Sign - Squint]; Fatima's mother said that Fatima's eyes sometimes looked in different directions. Her parents could not afford to take her to see an eye specialist, or an ophthalmologist, and they hoped that her eyes would become normal as she grew up.

Fatima's mother brought me a flash photo of her daughter taken by a relative a few months ago. In the photograph, you can see that Fatima's right pupil has a white reflection, rather than the usual 'red eye' seen in photographs taken with a flash [Early Warning Sign – White Pupil]. When light shines into the eye, for example when a flash photo is taken, the pupil looks white, instead of red; this happens when the tumour reflects the light. Fatima's mother remembers thinking that the white reflection was strange, but had no idea that it might be a sign that anything was seriously wrong. She has now learned that one of the very earliest signs of Retinoblastoma may be a so-called 'white pupil'.

Over the next few weeks, Fatima's right eye became swollen and she often rubbed it as if she felt some pain [Early Warning Sign; Pain and Swelling around the Eye]. Her mother noticed that Fatima had been bumping into walls, doors and tables [Early Warning Sign: Visual Loss]. Fatima's mother took her to the local general physician. The physician said that she should go to an eye specialist in Karachi to have

Fatima's eyes checked out. So the family borrowed the money for the journey to go to the government hospital.

## Examination steps

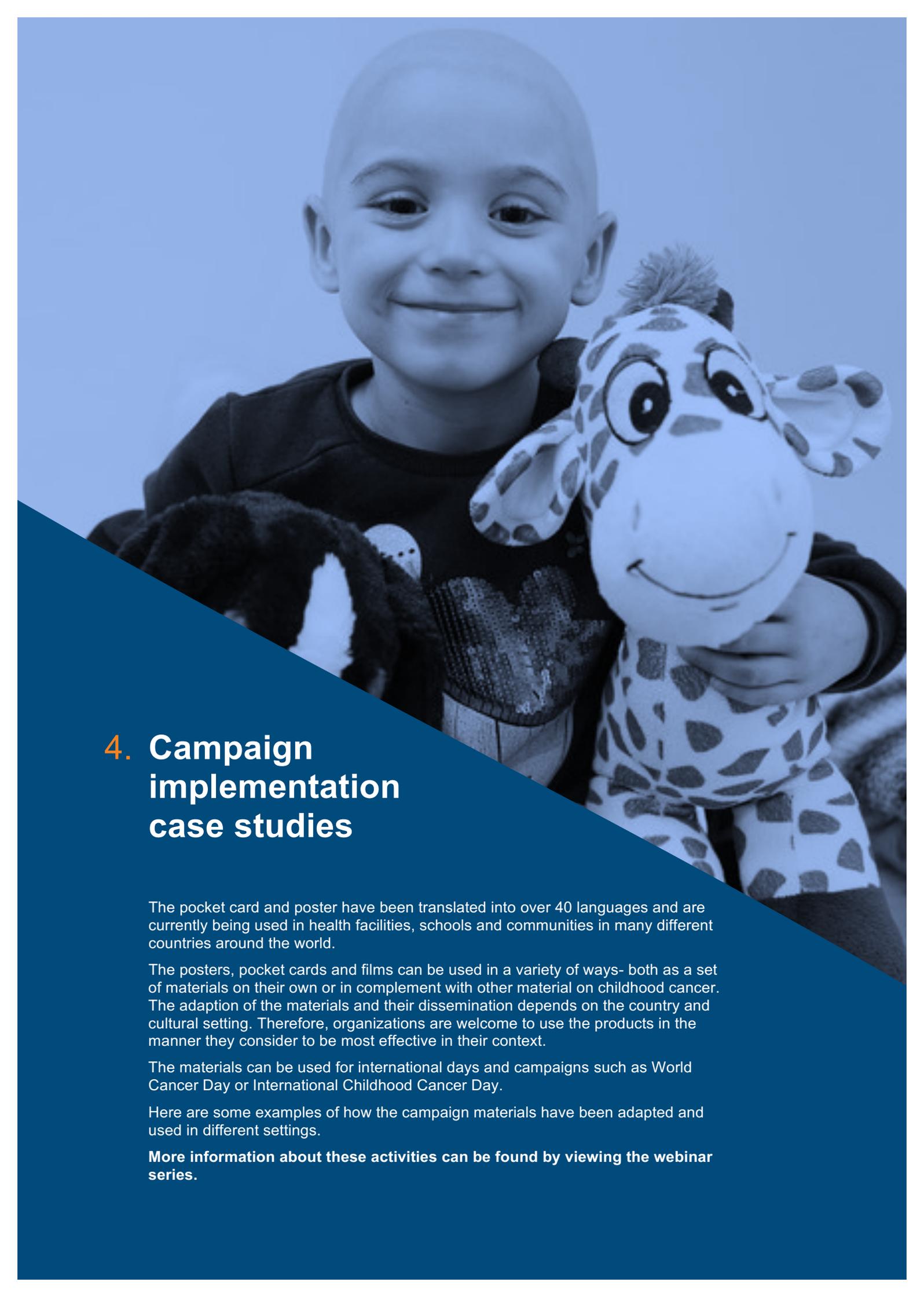
The eye specialist [an ophthalmologist] examined Fatima's eyes closely. He put some special drops into Fatima's eyes to make it easier to examine them; this is called dilation. He then checked her eyes with a flashlight, to see if she had a 'red reflex'; he assessed her squint, and he carried out some simple tests of Fatima's eyesight [insert of eye test image]. Then the ophthalmologist told Fatima's parents that he thought she had a tumour in her sore eye.

The ophthalmologist immediately said that Fatima should come here to the regional hospital in Karachi, which has a specialist unit to treat children with cancer. Here her tumour would be investigated, and she could receive specialist treatment, which he hoped would cure her.

When Fatima reached the hospital in Karachi where I work, she had an ultrasound scan and an eye examination under an anaesthetic. The doctors found an extensive tumour in her right eye and a smaller tumour in her left eye. Unfortunately, Fatima will have to have her right eye removed to take out the tumour and stop the cancer from spreading outside her eye. We hope to save her left eye by giving her chemotherapy. We do not know yet whether we can save the sight in Fatima's left eye, and so it is possible that she may become blind. Whatever happens, she and her family will have expert medical treatment from the team in the children's cancer centre.

## Take-home messages

- We know that the sooner Retinoblastoma is detected and treated, the better chance there is of saving the child's vision, and in some cases, preserving the eye. If Retinoblastoma is detected early, almost all children will be cured of their disease.
- If a tumour is left untreated, it will grow and move out from the eye and spread into other parts of the body such as the central nervous system and bone marrow and can be life threatening.
- Retinoblastoma is a condition that may sometimes be inherited in the genes which means that there is a risk of tumour in both eyes. Also, siblings may also be at risk of developing tumours in their eyes and therefore also need to be checked.
- Changes in a child's eyes or vision should always be taken seriously, as these changes could be a sign of cancer.
- A squint, swelling of an eye, pain, poor vision or the lack of a red reflex can be signs of the eye cancer Retinoblastoma. If you find two or more of these signs you should always send the child to be seen by an eye specialist.
- Families should be told that if they see a white pupil on a flash photograph they should take their child to be seen by a health care professional.
- Check the eyes of all babies and children who come to your clinic by looking for a red eye reflex using a flashlight. If instead of the red reflex you see a 'white pupil', send the child to a district hospital for a consultation with an ophthalmologist immediately.
- Your actions are critical in helping to save children's eyesight, and their lives, by identifying Retinoblastoma early, and referring children on for specialist treatment.

A young child with a shaved head is smiling and holding a giraffe plush toy. The child is wearing a dark-colored shirt. The background is a light blue gradient. The image is overlaid with a dark blue diagonal shape in the bottom-left corner, which contains the text.

## 4. Campaign implementation case studies

The pocket card and poster have been translated into over 40 languages and are currently being used in health facilities, schools and communities in many different countries around the world.

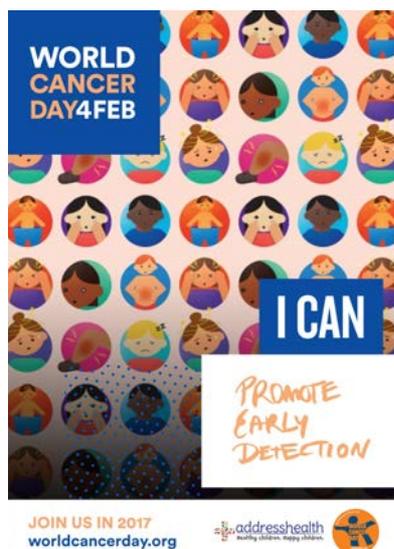
The posters, pocket cards and films can be used in a variety of ways- both as a set of materials on their own or in complement with other material on childhood cancer. The adaption of the materials and their dissemination depends on the country and cultural setting. Therefore, organizations are welcome to use the products in the manner they consider to be most effective in their context.

The materials can be used for international days and campaigns such as World Cancer Day or International Childhood Cancer Day.

Here are some examples of how the campaign materials have been adapted and used in different settings.

**More information about these activities can be found by viewing the webinar series.**

## World Cancer Day 2017 'We can. I can'



### Uganda - Bless a Child Foundation

Bless a Child Foundation (BCF) in Kampala, Uganda is an NGO that provides care and support for children with cancer. In raising awareness of childhood cancer, BCF disseminated information from the Signs and Symptoms campaign in different ways. This included holding a series of public lectures with professionals, hospital medical staff, members of the business community and parents. The information from the poster and pocket card was disseminated during these lectures using photographs and images of malignancies which resonate more in this setting than the campaign's cartoon style images.

In educating teachers and children about childhood cancer and cancer more broadly, BCF developed a more interactive and child friendly approach to learning. They used clowns, puppets and games in schools in a session lasting approximately 45 minutes to teach children about the early warning signs as well as to impart key messages related to health lifestyles and cancer prevention.



### Cameroon - Banso Baptist Hospital

The Banso Baptist Hospital (BBH), is part of the Cameroon Baptist Convention Health Services (CBCHS)- a non-profit, Faith based healthcare organization providing medical care across different provinces in Cameroon. Paediatric patients treated at the Banso Baptist Hospital in North West Cameroon are frequently referred from primary health clinics in the region. As the majority of children admitted with malignancies presenting to the Baptist hospitals have advanced disease (stage 3 or stage 4), staff from the paediatric oncology unit have been working to increase knowledge of the early warning signs of childhood cancer among health workers and parents.

Posters from the Signs and Symptoms campaign were posted in the main Baptist Hospital and in the satellite primary health care facilities. A nurse from the paediatric oncology unit visited the different facilities and gave a health talk explaining the different signs on the poster. PowerPoint case presentations, data and pictures of Cameroonian children with malignancies were also used as educational material so that health workers can recognize the early warning signs and refer for further testing and treatment.

In addition to health facilities, BBH staff used the signs and symptoms posters, pocket card and case presentations in churches, schools, with traditional healers and at the market. On International Childhood Cancer Day (ICCD) additional outreach was conducted using the materials in these settings. An additional pocket card has been designed with the name of the hospital in charge of childhood malignancies so that hospitals, traditional healers, teachers and parents know where treatment and care can be accessed. To date more than 10,000 brochures have been distributed.



## Chile - Fundacion Nuestros Hijos

In Chile, a Fight Against Cancer week is held every October. In 2014, the Fundacion Nuestros Hijos, a private, non-profit institution created by a group of parents of children affected by childhood cancer, teamed up with the Chilean Ministry of Health and distributed 16,500 flyers and 6300 pocket cards with the Signs and Symptoms information to nurses and doctors in primary health centres. Explanations of the signs and symptoms were delivered through small meetings with health workers in these facilities. The material was also used to provide information on childhood cancer in universities.

On International Childhood Cancer Day in 2017, the Minister of Health and FNH held a press briefing on the signs and symptoms of childhood cancer. This was covered by the media including CNN and National TV which covered the main symptoms in their televised segment.



## Multiple settings - World Child Cancer

World Child Cancer, a charitable trust based in the UK builds 'twinning' partnerships which link together hospitals in the developing world with childhood cancer units in developed countries. WCC distributed the UICC / SIOP / CCI early warning signs and symptoms posters to a number of partners in low-middle income countries. In most countries, the materials were found to be very useful and were distributed widely.

Overall more than 30,000 copies of the posters have been printed in Bangladesh, Malawi, the Philippines, Cameroon and Myanmar.

In both Myanmar and Malawi, the posters were also translated into local languages to improve accessibility amongst communities. The materials were sent to district hospitals and community health centres, with a wide reach across all countries.

In Bangladesh, the information has also been reprinted in the National Guidelines for the management of childhood malignancies, and in the Nursing Curriculum for Paediatric Oncology. Partners in Myanmar and Bangladesh also used the materials as part of training delivered in hospitals and with primary health workers.

In Malawi, the palliative care team helped to distribute the posters to community health centres and some were also passed on to traditional chiefs.

In Cameroon, the materials were used widely as part of training and International Childhood Cancer Day awareness events, and were also used to train traditional healers. Although no structured feedback has been collected, anecdotal evidence suggests that the information was well-received and there have been reports of increased referrals which could partly be attributed to the dissemination of these posters.



## Indonesia - Indonesia Care for Cancer Kids Foundation

The UICC/SIOP/CCI early warning signs and symptoms materials have been endorsed by the Indonesian Ministry of Health.

In February 2017, the Indonesia Care for Cancer Kids Foundation (Yayasan Kasih Anak Kanker ) in collaboration with the Public Health Faculty, Thamrin University, Dharmais Cancer Hospital and the Indonesian Ministry of Health, Sub Directorate for Cancer launched a research study on "Basic Orientation on Childhood Cancer in West Java Province and DKI Jakarta Province, Indonesia 2017". This project financed by Childhood Cancer International (CCI) and Roche Indonesia utilized the UICC/SIOP/CCI infographic and conducted training sessions for primary health doctors and women empowerment cadres (community health volunteers that are engaged by the local primary health centres).

The aim of the research is to evaluate the effectiveness of basic orientation on childhood cancer (level-1 training, level-2 training and public education) in increasing communities' knowledge, attitudes and practices (KAP) on childhood cancer in Bekasi and Depok, West Java and North Jakarta and East Jakarta.

The orientation sessions targeting health workers included 160 health professionals (primary health doctors, midwives and nurses) from North & East Jakarta, and 199 (primary health doctors, midwives and nurses) from Depok and Bekasi, totalling 359 participants overall.

The orientation targeting female empowerment cadres included 349 participants from Bekasi, Depok, North Jakarta and East Jakarta.

For both groups, an evaluation pre-test and post-test was given before and after the training. These tests were prepared in collaboration with CCI and the Public Health Faculty of Thamrin University.

The orientation training on childhood cancer was given by 4 specialists from Dharmais National Cancer Hospital, Jakarta and used the UICC/SIOP/CCI infographic.

A public awareness and education campaign on Childhood Cancer Early Warning Signs (CCEWS) is also planned. This will include conducting a baseline Community Survey of Knowledge, Attitude and Practice on Childhood Cancer and conducting a follow-up study at 3 month, 6 month and 12 month intervals after the Public Education on Childhood Cancer is implemented.

A report of these activities is expected to be completed by the end of 2018.



## 5. Further reading

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