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Review

International twinning partnerships: An effective method of improving diagnosis, treatment and care for children with cancer in low-middle income countries[☆]

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ABSTRACT

Given the huge disparity in the chance of survival for children with cancer born in low income countries (LICs) compared with those in high income ones, there is an urgent need to assist those striving to support, palliate and offer curative treatment in resource limited settings. International twinning partnerships offer the opportunity to provide advice, expertise, support and technology transfer from established paediatric oncology units to developing ones in order to help them overcome the challenges facing them. It may help them to avoid the mistakes made over the last 50 years during which childhood cancer survival has progressed in high income countries from little expectation of cure to 75–80% long term survival. Projects must be locally driven by the team in the LIC, but volunteers and funding organisations can help to make progress possible. There is mutual benefit for all concerned.

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Introduction

One of the medical success stories of the last 50 years has been the progressive improvement in survival for children with cancer, from little expectation of cure in 1960 to 75–80% long term survival in 2003 [1,2]. At least that is the picture in high income countries (HICs). In low-middle income countries (LMICs), where 80% of children actually live, survival is 30% at best and under 10% in most low income countries [3–5]. In 2008 Dr. Margaret Chan, Director General of the World Health Organisation (WHO) stated “The rise of cancer in less affluent countries is an impending disaster.”

Despite an increasing international recognition of the threat of non-communicable diseases, including cancer, to the health of nations the plight of children who develop cancer is frequently overlooked [3]. There are a number of reasons for this. Childhood cancer represents under 2% of the world’s cancer burden [6] and the pattern of malignancies is very different to that seen in adults. There is a greater possibility of prevention, by reducing excess environmental exposures, (e.g. smoking, diet, alcohol, sun-exposure) in adult cancer than in children. Although, as a result of a concerted global effort, under 5 year mortality rates (U5MR) have been significantly reduced over the last 15–20 years (from 12 to 6.9 million in 2011) [7], most deaths in children continue to result from communicable diseases (e.g. malaria, pneumonia, Tb, HIV, diarrhoea, measles) with or without associated malnutrition [8–10]. In many Sub Saharan African countries U5MR still exceeds 160/1000 live births [5,7,11,12], with cancer estimated to account for only 0.14/1000 deaths.

However eminently treatable tumours, such as Burkitt lymphoma (aetiologically linked to EB virus, chronic malarial infection and malnutrition) predominate in Sub Saharan Africa, especially. It is highly relevant to the development of health services that 50% and 32% of under 5 deaths worldwide occur in Africa and Asia respectively. As the global efforts to decrease communicable disease begins to succeed, childhood cancer emerges as a more significant threat to lives especially where socio-economic conditions are improving. This is a pattern observed in higher income countries in the 1950s. With the absence of true population based cancer registries in most low-middle income countries the precise burden of childhood cancer has to remain an estimate. Based on the data where registries do exist, the rates range worldwide between 80 and 150 cases/million children. On this calculation there would be between 160,000 and 200,000 new cases worldwide per year, with 80% of those occurring in LMICs [6,13]. The majority of these children will die following; very late or mis-diagnosis, or even missed diagnosis; inability to afford therapy, toxicity and co-existing diseases and malnutrition. Deprived of any chance of cure, the majority receive little or no relief of symptoms, especially of pain.

All children, irrespective of where they live, really do deserve better from the global community. It should not be beyond the ability and vision of professionals, parents/families, governments and NGOs/charities to redress the current inequality of access to care [14]. Many childhood cancers are curable at an affordable cost even in countries with only basic healthcare systems. Burkitt lymphoma [15,16], nephroblastoma [17,18] and retinoblastoma [19,20] are good examples and account for nearly 50% of tumours seen in many Sub Saharan countries. Acute lymphoblastic leukaemia, the commonest single malignancy seen in HICs, has an increasing incidence in LMICs as socio-economic conditions improve, as was seen in the UK, Europe and USA in the 1950–1960s. Affordable essential investigation and therapy needs to be developed to increase survival in LMICs [21,22].

International twinning partnerships can provide a way to effectively transfer expertise, skills and knowledge acquired in the HICs over the last few decades to try to improve; speed and accuracy of diagnosis, supportive care, delivery of therapy safely and to

Table 1
Key steps in twinning.

-
- As cancer emerges as a life-threatening risk
- Local recognition of a need to develop a service
 - Strong local medical/nursing leadership
 - Creation of a team/hospital unit
 - Local community mobilisation (friends/parents)
 - Recruitment to the cause of hospital management/health planners/health ministries
 - Then external support sought/advice/funding
 - Long term collaboration with a twinned centre
-

Source: Eden [27].

provide good palliation for children in LICs where local doctors and nurses are trying to help children with malignancies. The twinning model was pioneered by the St Jude Children’s Research Hospital (Memphis, USA) International Outreach Group [23,24] and by the Milan-Monza Group from Italy [25]. World Child Cancer, an International Charity, was created in 2007 to raise funds, create twinning partnerships worldwide, and to attempt to emulate the successes of those pioneers and to improve supportive, palliative and curative care in more LIMC countries worldwide [26].

The concepts of twinning

Given this huge disparity in survival between children in HICs compared with LICs the concept that the lessons learnt over the last few decades in higher income countries might be able to assist doctors and nurses facing the dilemma of what more they could do for the children with leukaemia and solid tumours presenting at their limited resourced hospitals. This has led to the creation of twinning partnerships. Table 1 shows the key steps required to establish such a partnership.

Inherent in successful twinning is the concept that it must be locally led by a developing team in the resource limited country if it is to be successful and sustainable. The solutions to the challenges (see Table 2) must come from the local team not dictated from outside the country but two-way transfer of expertise, advice, knowledge and skills can help to speed up progress and help to avoid the pitfalls experienced in HICs over the last few decades. Above all the plans must be locally affordable if they are to be sustainable. There is immense mutual benefit to be gained by exploring what is “essential” in terms of investigation, supportive and palliative care, and curative treatment. Truly optimal care may take some longer time to develop. In any twinning project, long term commitment and mutual respect from both sides of the partnership is crucial. The challenges/obstacles must all be addressed within the context of any twinning programme.

Poverty

Ribeiro et al. [5] reported that the strongest correlation with survival from childhood cancer in the first 10 countries supported by the “My Child Matters” Project was governmental health care

Table 2
Obstacles to be overcome in starting the treatment of young people with cancer.

-
- Individual family, community, national poverty
 - Other overwhelming health priorities (e.g. communicable diseases)
 - Other societal problems – natural and man-made
 - Lack of cancer incidence/survival data (cancer burden/survival)
 - Lack of awareness of signs/symptoms/perceptions of incurability
 - Lack of access to diagnosis/treatment
 - Lack of supportive/palliative care
 - Lack of trained/experienced staff
 - Lack of ability to retain trained staff
 - Major infrastructural problems e.g. transport to hospital/home
-

Table 3
Trends in under 5 mortality 1990–2008 (rate/1000 live births).

Region	Fall in deaths	% reduction	% of worldwide U5MR
Africa	168–132	21%	51%
North Africa/mid-East	77–43	44%	5%
Sub-Saharan	184–144	22%	50%
Asia	87–54	38%	42%
South Asia	124–76	39%	32%
East Asia/Pacific	54–28	48%	9%
Latin America/Caribbean	52–23	56%	3%
Industrialised Countries	10–6	40%	1%
Least Developed Countries	179–129	28%	40%

Source: Data derived from You et al. Lancet 2012 [12] and UNICEF, WHO, World Bank, UN [7].

expenditure per capita and the resulting numbers of doctors and nurses employed per 1000 population. In the absence of state funding the full costs of most investigations and treatment for cancer fall to the family. When this is combined with lost earnings when a mother/older sister has to spend time in hospital with the child, it is not surprising that there is a high rate of treatment refusal and abandonment in LICs (up to 60%) [28–30]. Premature curtailment of treatment can only be overcome if the cost to families, of drugs [26], transport to and from hospital [31] and household income disruption are addressed [30]. The need to complete therapy must be stressed/communicated well to families [29]. The influence of local 'healers' in offering cheaper 'remedies' cannot be over-emphasised (they will not cure the child) [32,33].

Other overwhelming priorities

Table 3 shows the progress made in reducing U5MR. 90% of all under 5 deaths occur in 42 low-middle income countries. Concerted efforts to reduce deaths from communicable diseases have been made but over 40 countries show negligible progress in doing so. Curative care for children with cancer cannot at present be a priority in those countries, but in all countries relief of symptoms surely should be a critical priority. Paradoxically in those countries where there has been a significant reduction of U5MR, cancer with all of its complexity is emerging rapidly as a significant threat to the lives of children.

Regrettably, reductions in governmental overseas aid donations by many HICs may slow progress in attempts to reduce the risks to children of both communicable and non-communicable diseases. Disasters, natural and man-made inevitably distract from and reduce focus on health concerns. It is no coincidence that those countries with the worst track-record in improving maternal and child health are those involved in civil war or political strife.

Cancer registration

If you do not know the true population incidence, mortality and survival for any disease it is impossible to assess progress in disease control, and the burden that disease represents for a population. Regrettably a minority of countries worldwide have such population based cancer registries. The best that can be currently achieved is a reliable 100% ascertainment of data on a hospital basis using reliable ward logs, spread-sheets and ultimately online registration.

Awareness of signs and symptoms

Lack of awareness of the meaning of the signs and symptoms of disease by patients, families and health care professions leads to late diagnosis, misdiagnosis, or missed diagnosis altogether.

The time from first symptom onset until diagnosis and start of treatment is termed 'symptom interval' which has been extensively investigated in high income countries as a possible cause of treatment failure. In high income countries the principal reasons for long symptom intervals are due to professional and system delays especially for bone and brain tumours [34,35]. In low income countries there may be considerable delays in parents recognising the seriousness of symptoms and in being unable to access health care. Inadequate training of staff at health clinic level may lead to either no or delayed referral of patients to secondary care [36,37]. Evidenced suggests that at secondary and tertiary care levels, clinical signs are most often recognised quickly. Speedy presentation does relate to tumour biology so that children with leukaemia for example with florid multiple signs generally present much quicker than those with solid tumours. Children with advanced stage disease are much more likely to be impossible to cure and difficult to palliate.

Lack of diagnostic ability/capacity

There are three key components which influence long term survival; access to diagnosis, access to treatment and effective therapy. Good clinical practice and basic imaging and laboratory tests can assist the diagnosis in most children without the very sophisticated investigations available in HICs. However good pathological confirmation of tumour type is important and some degree of technology/expertise transfer maybe crucial in the early stages of service delivery [11,38–40]. Hospital therapeutic capacity has to be increased when more patients present. Drug supplies of essential cytotoxic and supportive drugs has proven to be a major issue despite all of the necessary 19 (generic and off patent) drugs to treat all common childhood cancers being on the WHO Essential Medicines List for childhood cancer [41,42]. Yet some of those drugs are not consistently available and/or affordable in even the 156 countries who have signed up to the Essential List. Target 17 of Goal 8 of the Millennium Declaration stated "the need for cooperation with pharmaceutical companies to provide access to affordable essential drugs in developing countries" [43]. Most LICs do not produce their own drugs so importation is essential. There is an urgent need to address globally, the production, distribution and safety of such generic, off patent drugs for worldwide usage [44–46]. Nowhere is this truer than for palliative care and especially pain relief. All the essential drugs are approved by WHO [47]. However there remains in many countries a stigma associated with prescribing, dispensing and usage of opiates, based often on false beliefs regarding addiction. Again a worldwide strategy and concerted effort is required to overcome this hurdle [46].

Effective therapy in HICs is often complex, delivered ideally within randomised clinical trials and expensive. The aim is to cure at least 80% of all cases and hopefully 100% within the foreseeable future. The stage reached in these countries has taken 50 plus years to achieve.

Modified, graduated intensity strategies have been recommended for use in LICs so that once experience has been gained with low intensity therapy and toxicity minimised then therapy, if affordable, can be intensified [22]. Successful use of basic therapy in individual countries has been well documented [15,16,18] and the French African Paediatric Oncology Group have developed successful collaborative multicountry studies using such strategies for Burkitt lymphoma and Wilms tumour especially [17,48]. Similarly major progress with survival has occurred in Central and South America using collaborative protocols as part of twinning partnerships with St Jude Research Hospital, Milan-Monza, and Hamilton Ontario Canada [49]. A crucial component of the

Table 4
Crucial elements of each partnership.

- Raising awareness/potential to cure
- Increase speed and accuracy of diagnosis
- Increase diagnostic/therapeutic capacity
- Reduction of treatment refusal/abandonment
- Ensure supply of good quality/affordable medicines
- Develop locally affordable therapy
- Focus on good supportive/palliative care
- Registration of all patients
- Train and retain staff
- Support families/create parent groups
- Develop long term sustainability

collaborative groups, especially of the MISPHO programme has been the regular educational focus for oncology nurses, supportive care, tumour specific updates, epidemiology and progressively cancer research methodology [49].

The International Society of Paediatric Oncology PODC group have recently produced a series of Guidelines for the Management of Children in low income settings for Wilms tumour [50], Endemic Burkitt Lymphoma [51], Kaposi Sarcoma [52], Retinoblastoma [53] and Supportive Care [54]. A six country collaborative project to convert the guidelines for Wilms tumour into a specific study is being activated. More guidelines for other tumours and the development of other potential collaborative studies are being developed.

Training and retention of staff

Underpinning all aspects of care must be appropriate training and retention of staff if therapy is to be successful and safe. In the past too many doctors and nurses were recruited away to HICs for training and better paid posts. Their acquired new skills were consequently lost to their home country. In most twinning programmes the majority of training for nurses and doctors is organised in country or loco-regionally, in the same continent. If a doctor or nurse does go abroad for specific training it is crucial that there is a job for him/her to return to with a salary commensurate with the greater expertise, knowledge and value to the home country/hospital. In country training programmes should consist of short (3- to 7-day) intensive workshops for nurses and doctors. The topics should be decided by the local team and visiting colleagues from HICs selected to ensure they have specific expertise in the subjects to be covered. Careful liaison prior to such teaching is essential to ensure that what is discussed can be achieved locally. All aspects of care/patient management (diagnosis, supportive, palliative and curative care) need to be included. Between such workshops ongoing dialogue using; internet – conferencing (e.g. Cure4Kids – <http://www.cure4kids.org> [55] and/or www.medicineafrica.com [56]), regular telephone conferencing/emails and multidisciplinary meetings for patient review, are all very important.

Challenges – how to help with them?

All of the above challenges naturally lead to a need to include all of the features shown in Table 4 within any twinning programme.

Awareness

This must include raising awareness of the signs and symptoms of cancer in children for the public so that families seek help in a timely fashion for cardinal features. This can be achieved by using poster campaigns targeted at health clinics, schools, churches, etc., wherever adults meet. The messages must be clear, locally acceptable (there does remain considerable stigma associated with cancer in many cultures) and repeated on a regular

basis [57]. The presence of particular signs and symptoms needs to trigger a speedy seeking of medical help. Such campaigns can be augmented with media campaigns using radio, TV, newspapers, etc.

At the same time community health workers, nurses and doctors need to be educated through not just posters but by publicity and inclusion in training workshops/visits of team members from the twinning programme wherever possible.

The focus of awareness needs to be on a speedy diagnosis which can provide a chance of cure and more rapid relief of symptoms. Parents/parent groups/survivors of cancer can play a crucial role in such awareness campaigns. Public awareness of survivors increases belief in curability.

Diagnosis

Speed of diagnosis should reduce the incidence of late stage disease and toxic deaths resulting from poor health and malnutrition at time of presentation which is currently very common in LICs [58].

Accuracy of diagnosis can present a problem because of lack of diagnostic imaging, laboratory investigation and a paucity of trained pathologists and of the sophisticated diagnostic tests available in HICs. Use of “remote” tele-pathology can help to train/assist trained pathologists (who often do not have expertise in childhood cancers) to make more precise diagnosis (not just a “small round cell tumour”). Building capacity and quality of diagnostic services must be a core component of any twinning. Cameras on microscopes, internet exchange of images, web-based conferencing and technology transfer should/can be included wherever a need exists [39].

Reduction of treatment refusal/abandonment

In many LICs treatment refusal/abandonment maybe as high as 60% [28,29,30,59]. An increased belief in curability should emerge after adequate awareness raising. However the major causes of untimely cessation of treatment do relate to the cost of therapy (drugs, transport to and from the hospital and loss of earnings within the family) and major family disruption where every family member has a key role. In addition when a child starts to look and feel better after preliminary therapy, families do stop treatment because they feel their child is now ‘cured’. Failure to communicate well about the need for a full course of treatment has been cited as critical in this happening [29].

Since in most low incomes settings, there is a lack of a comprehensive health service financed by the Government, costs fall on families. In the short to medium term a degree of subsidy for drug and travel costs can be met from external aid grants made by the Twinning Project Organisation but also by local non-governmental organisations created within country [60]. In the long term all involved need to work with national governments for sustainability.

There is also an urgent need to work internationally to reduce the cost of off patent generic cytotoxic and supportive drugs [21,24,29,43,45,46,61,62] and to ensure consistent production and a worldwide distribution.

Production of effective and affordable therapy

The recognition that it is necessary to graduate the intensity of therapy to minimise cost and toxicity but yet offer chance of cure has been documented earlier. Some challenge the “ethics” of having different therapy for different children but when the alternative is certain death most practitioners do prefer to use what is tolerable. The concept of graduated intensity protocols enables

increasing intensity when patients are seen to tolerate level one treatment. This is after all what led us to the current 75–80% cure rates in high income countries.

Supportive and palliative care

Palliation of symptoms should start when the patient presents. The relieve of symptoms especially pain must be a fundamental component of all cancer therapy. Where a patient (as often happens in LICs) presents with very advanced disease, often co-existing medical conditions and malnutrition, curative care may not be possible. Such children deserve the very best palliation. It is essential that all involved in caring for children in LMICs are trained in palliative care (from medical school and nurse training onwards) and that as a global community we strive to make available all necessary essential drugs to achieve that worldwide [47].

Data registration

In the absence of total population cancer registries, a good 100% ascertainment hospital register must suffice. Funding may be required for computer equipment, training and the salary of a data manager to work with the clinical team to run the registration. We have encouraged the use of web database (POND Database – www.POND4kids.org) for World Child Cancer projects. This was created by St. Jude Hospital and provides an ability to share anonymised data with funders for progress reporting but also as a clinical network develops within each country (e.g. Bangladesh, Ghana, Philippines [26]) or even between countries (AHOPCA [49]). Such registration enables assessment of progress in reducing treatment, abandonment, late diagnosis, toxic deaths and improving survival but also provides invaluable evidence to health planners of the cancer burden at least within the specific hospitals. With a developing network a more clear picture of countrywide childhood cancer burden can emerge.

Training/retention of staff

Clearly this must be at the heart of all twinning partnerships. Funding should be available for visits of a small number of doctors/nurses from the HIC twinning partner hospital to hold training workshops with content proposed by the local team. It appears to work best if there are specific sessions for nurses and doctors separately but with some common time as well [49,63,64]. Well worked out long term training modules are ideal but in all cases any educational momentum established by workshops needs to be complemented by on-going regular emails. Skype calls and online training site usage such as Cure4kids [65]. These all can provide on-going advice, transfer of expertise and exposure to a wide range of literature and experience. This website is free to registered users [65].

Within a twinning programme doctors and nurses from HICs donate their time and expertise voluntarily so that a huge amount can be achieved with relatively low expenditure (travel and accommodation only). Clearly sometimes it is appropriate that staff from the developing centre do spend time abroad. Preferably this should be for short specific educational/training needs or to attend an international congress which includes a significant relevant educational component (e.g. the SIOP Annual meeting). The focus must be on retention of staff within country. Some scope for loco-regional training within continents is emerging and this reduces the risk of losing trainees to HICs [66,67].

Supporting families

Support should be provided to either establish de novo parent groups or help those already in existence to clearly help new families through their child's illness but their input to awareness campaigns, reduction of treatment abandonment/refusal and developing long term sustainability is crucial. Many parent groups in LICs start initiatives to raise funding for aspects of the service themselves.

Long term sustainability

Advocacy by the local team and the twinning partner to hospital, community, NGO and governmental authorities is necessary from the outset if long term sustainability in country is to be achieved. Unlimited duration of external aid can demotivate countries from developing independence financially for critical medical services. The twinning partnership should and does almost always provide long term friendship and mutual support between individual doctors and nurses and hospitals in both the LICs and HICs where projects are developed. Such linkage persists beyond the duration of actual funding.

World child cancer twinning – a model?

Following the twinning model outlined above and adapting it to the needs of each individual project, World Child Cancer creates twinning partnerships between hospitals in LMICs and HICs to encompass all of the aspects which make a partnership successful.

World Child Cancer acts as the facilitator and project manager for these partnerships and provides essential funding. Often for healthcare professionals the desire and willingness to make a difference and use their skills to help inform others is there, but a heavy workload and restrictive employment mean that it is difficult to organise an effective twinning partnership without the help of an external organisation. World Child Cancer takes on a project management role and ensures that funding is secured for all aspects of the project. In this way the professionals who are keen to dedicate their time and direct their skills are relieved of administrative burden of managing a project.

World Child Cancer is fortunate to have recruited some of the world's leading child cancer units and paediatric oncology doctors and nurses to work on its projects as volunteers. The time and expertise that they donate to projects is at least equal in value to the financial aid that the charity contributes to projects (see Fig. 1).

Since 2007 the charity has facilitated nine twinning partnerships (in Ghana, Malawi, Mozambique, Cameroon, Mexico, Colombia, Pacific Islands, The Philippines and Bangladesh).

Most projects are based in a tertiary teaching hospital in a LMIC and twinned with one or two hospitals in HIC's. The charity has recruited hospitals from UK, The Netherlands, USA, Canada, Singapore and South Africa to act as partners to the units in the resourced limited countries (see Table 5).

Project selection criteria

World Child Cancer works in locations where it is confident that there is the basis for progressing a practical and realistic development plan. There are several selection criteria for considering a new project including:

- *Location* – preferably in a country with stable governance, no civil war and essentially is a place to which it is safe to send medical volunteers.

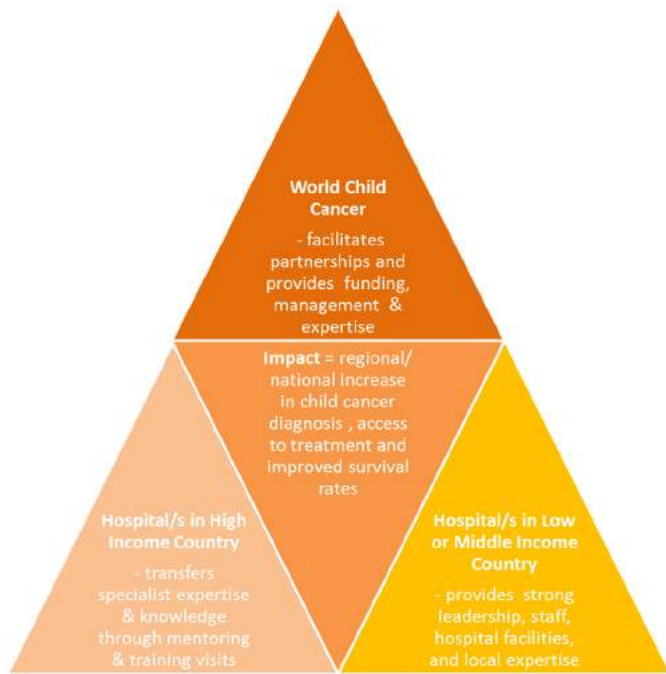


Fig. 1. The three-way relationship in a World Child Cancer twinning partnership.

- **Health statistics** – the country should have made significant advances in reducing the under-5 mortality rate over the last 10 years; it is often around this time that cancer begins to emerge as a common cause of death in children.
- **Leadership** – it is essential that there is a strong local project leader in place, preferably a doctor working in the paediatric oncology unit, who has benefited from some specialist experience or training in paediatrics and ideally in paediatric oncology and is capable (and willing) to run the project
- **Feasibility** – the charity looks for realistic and achievable objectives which focus on curing curable and palliating the incurable. The local project leader is asked to submit a 5-year development

plan (with the input of the twinning partner wherever possible and a member of the Project Committee of World Child Cancer) including measurable aims and objectives year on year.

- **Accountability** – there must be a willingness to be accountable for the funding that the project receives. The charity requires 6-monthly financial and qualitative reports to assess the impact against agreed outcomes and outputs and yearly quantitative reports on progress (for example numbers of patients seen/trends, changes in levels of late stage disease, treatment refusal/abandonment, toxic deaths, and survival).
- **Sustainability** – there must be the potential to develop long-term sustainability after funding from World Child Cancer comes to an end. This includes both the potential for increased government funding and of raising funding through the local parent support groups and other local non-governmental organisations.
- **Scalability** – the charity’s approach focuses on identifying a tertiary hospital in a LMIC which, through support from a twinning partnership, becomes a centre of excellence and then a hub of a network of satellite centres, culminating in child cancer treatment being accessible across a country or region. See Fig. 2.

Project development process

The process of identifying and selecting a project can take between one to two years and involves the input of the charity’s Project Committee which is made up of experts in child cancer treatment and care from HIC’s and LMIC’s (see Fig. 3).

Benefits of twinning

Twinning is a two-way transfer of expertise and skills which has benefits for hospitals and healthcare professionals for both the HIC and LMIC’s. It is clear that there are huge benefits to the receiving healthcare system in the LMIC through the twinning partnership programme:

- Most importantly, child cancer survival rates can be improved and access to treatment increased.

Table 5
 Location of current operational world child cancer funded twinning partnerships.

Project location	Twinning partner/s	Cases p.a.	Start date	Stage in development
Africa				
Cameroon Cameroon Baptist Hospital Convention	Tygerberg Children’s Hospital/Stellenbosch University, SOUTH AFRICA	150	2012	Stage 2 – development of twinning partnership and local expertise
Ghana Korle Bu Teaching Hospital, Accra	Royal Hospital for Sick Children, Edinburgh, UK	220	2010	Stage 3 – development of centre of excellence in Accra
Malawi Queen Elizabeth Central Hospital, Blantyre	VU University Medical Centre, Amsterdam, and Royal Victoria Infirmary, Newcastle, UK	260	2009	Stage 3 – development of centre of excellence in Blantyre
Asia				
Philippines Southern Philippines Medical Centre, Davao (Mindanao)	University Hospital, Singapore and St Jude Children’s Research Hospital, US	250	2010	Stage 4 – development of network of satellite centres across Mindanao linked to Davao centre of excellence
Bangladesh Bangabandhu Sheikh Mujib Medical University, Dhaka	British Columbia University, Vancouver, CANADA and University College Hospital, London, UK	400	2012	Stage 3 – development of centre of excellence in Dhaka
Latin America				
Colombia Instituto Nacional de Cancerlogia, Bogota	Boston Children’s Hospital/Dana-Farber, Boston, US	300	2009	Stage 3 – development of centre of excellence in Bogota
Multi-Country Projects				
AHOPCA – Central American Paediatric Haematology–Oncology Project	St Jude Children’s Research Hospital, USA and POGO, Ontario, Canada	1000	2012	Stage 5 – development of network across El Salvador, Nicaragua, Panama, Dominican Republic, Costa Rica, Honduras, Guatemala

Our Approach

5-10 Year Strategy

Each of our projects following a 5-10 year strategy, depending on what stage of development they are at when World Child Cancer funding is agreed.

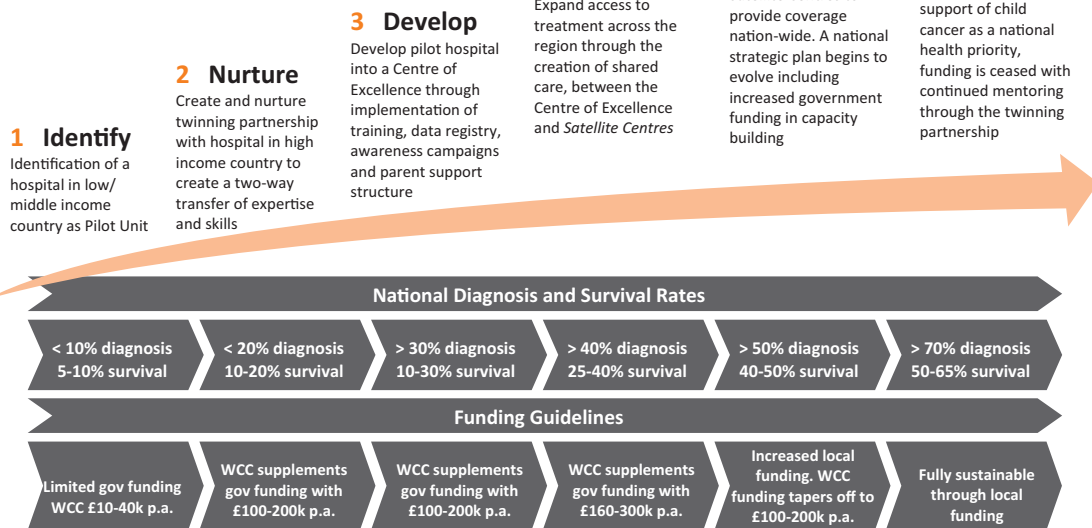


Fig. 2. Our approach 5–10 year strategy each of our projects following a 5–10 year strategy, depending on what stage of development they are at when World Child Cancer funding is agreed.

- Healthcare professionals in LMIC's gain specialist training from knowledgeable and experienced healthcare professionals at no cost or detriment to their own system.
- Locally appropriate treatment protocols are developed and implemented.

- The collection of statistical data is improved allowing an overview of the problem in the country to be clearly understood for the first time.
- Volunteers often bring donated equipment for the developing unit, and knowledge of how to use that equipment.
- Extra funding is provided to fund staff posts, (for example data managers, nurse salary supplementation for increased responsibility to assist retention of key staff), improve facilities and purchase drugs. Funding should be time limited for staff in order to create local sustainability.
- Guidance is offered to the local support groups.
- Knowledge of other healthcare systems is gained and long-lasting friendships developed.

The benefits to hospitals and volunteers from HIC's are less well understood but are still significant:

- Volunteers learn to work in very different environments from the ones they are used to encouraging problem solving skills and creativity.
- They become educated in the use of locally appropriate techniques and treating children with very few resources.
- New research opportunities are possible by mutual agreement between the two units – academic ownership must lie with the developing unit team.
- Volunteers develop an improved knowledge of global health.
- Their assumptions are challenged and they gain an increased cultural understanding and career commitment.
- There are learning opportunities for CPD.
- And finally, as for LMIC healthcare professionals, long-lasting friendships are made, both professionally and personally (see Fig. 4).

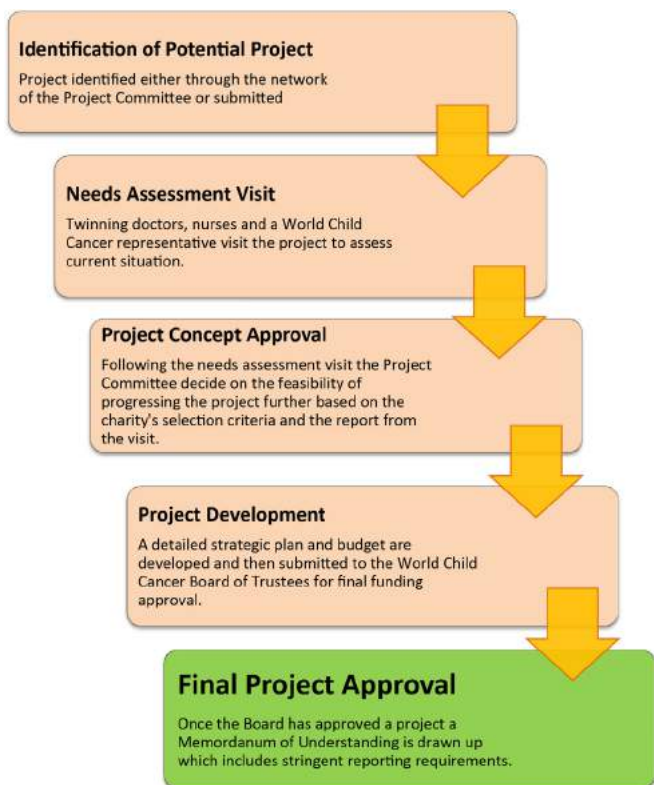


Fig. 3. Model for project development process.



Fig. 4. Mutual benefits of twinning partnerships.

World Child Cancer currently has seven operational twinning partnerships. Case studies from the projects in Malawi and The Philippines are outlined below to show the impact that a twinning partnership can have on diagnosis, treatment and care.

Malawi	
	<p>Project Location: Queen Elizabeth Central Hospital, Blantyre</p> <p>Twinning Hospitals: Royal Victoria Infirmary, Newcastle VU Medical University Centre, Amsterdam</p> <p>Project Leader: Professor Elizabeth Molyneux, OBE</p> <p>Twinning Mentors: Dr Simon Bailey and Dr Trijn Israels</p> <p>Start Date: 2009</p> <p>Stage: Stage 3</p> <p>Support: £140,000 p.a.</p> <p>Expected no. of cases: 900 cases per year</p> <p>Per Capita Income of Malawi: \$330 (2010 data/UNICEF)</p>
<p>Context</p> <p>The most common cancers in children are Burkitts lymphoma, Wilms tumour, retinoblastoma, Kaposi sarcoma and acute lymphoblastic leukaemia – all of which are treatable at an affordable cost with generic drugs and simple treatment protocols. These cancers account for about 60 – 70% of all cases.</p> <p>There are two main tertiary hospitals in Malawi – the Queen Elizabeth Central Hospital (southern Malawi) and Lilongwe Central Hospital in the capital (central Malawi). At the start of the project QECH diagnosed 160 children with cancer a year and Lilongwe about 50.</p>	<p>Challenges in 2009:</p> <p>QECH has been treating children with cancer since 1995. The hospital was achieving some success but there were still some major challenges to overcome:</p> <ul style="list-style-type: none"> • Many patients presented with advanced symptoms because of low awareness of child cancer and its potential curability; • There were too few doctors and nurses trained in treating children with cancer; • There was an unreliable supply of drugs because of funding; • Patients often abandoned treatment or did not return for follow up treatment; • There was no accurate data on child cancer incidence and outcomes of diagnosed patients; • Locally appropriate protocols were not in place for most cancers.
<p>Strategic Objectives 2009 to 2013:</p> <ul style="list-style-type: none"> • Develop QECH into a centre of excellence in child cancer diagnosis, treatment and care; • Build capacity at QECH by improving facilities and training staff in child cancer treatment and care; • Increase access to treatment for children with cancer in southern Malawi; • Improve survival rates for diagnosed children at QECH; • Develop reliable statistics on child cancer; 	
<p>Activities</p> <ul style="list-style-type: none"> • Implementation of training programme for doctors and nurses led by twinning mentors. • Refurbishment of the child cancer ward. • Establishment of child cancer registry. • Introduction of locally appropriate protocols. • Poster awareness campaign. • Support for parents by providing food costs whilst at hospital and reimbursement of transport costs for follow up treatment. 	<p>Impact of Funding to Date:</p> <ul style="list-style-type: none"> • Access to treatment has increased by 63%. • Survival rates for Burkitts lymphoma now 60%. • Survival rates for Wilm tumour are 47% • Survival rates for retinoblastoma and leukaemia now at 20%. • A child cancer registry has been recording all new patients since 2010. • Fewer patients are presenting with advanced cancer. • Abandonment of treatment is less than 5%. • QECH is now a centre of excellence in child cancer treatment.
<p>Future Development:</p> <p>The next stage in development is for the Queen Elizabeth Central Hospital to become a hub of a network of satellite treatment centres (from Stage 3 to Stage 4). Plans are underway to identify suitable hospitals to form the network. Funding will be provided for training, facilities, child cancer databases, salaries and drugs. Discussions are already underway with the Ministry of Health to improve the provision of long-term funding for child cancer treatment and care in Malawi.</p>	

Philippines



Project Location: Southern Philippines Medical Centre, Davao, Mindanao

Twinning Hospitals: University Hospital, Singapore
St Jude Children's Research Hospital, USA

Project Leader: Dr Mae Dolendo

Twinning Mentors: Dr Catherine Lam and Prof. Allan Yeo

Start Date: 2009

Stage: Stage 4

Support: £160,000 p.a.

Expected no. of cases: 900 to 1200 in Mindanao per year

Per Capita Income of Philippines: \$2,050 (2010 data/UNICEF)

Context

The Philippines is a low-middle income country which has made significant improvements in reducing under-5 mortality since 2000. However, there is still a huge disparity in income with many Filipinos' living on less than \$2 a day. Incidence of child cancer is similar to developed regions with a third of cases being leukaemia's.

The Southern Philippines Medical Centre in Davao City on Mindanao, the second largest island in the Philippines, provides tertiary healthcare for a population of 25 million people. The Centre has 25 dedicated beds for children with cancer. In 2009 about 100 children were diagnosed and treated. The centre receives some government funding but families are still required to fund drugs.

Challenges in 2009:

The Southern Philippines Medical Centre has been providing treatment for children with cancer for around 15 years. Although the staff have achieved a high level of competency and facilities are good, there are still major challenges to improving survival rates in 2009:

- Survival rates were around 30% in 2009 for diagnosed children.
- Lack of awareness resulted in late diagnosis for around 70% of patients.
- Under-diagnosis was a significant issue with only 100 cases of child cancer diagnosed in a region with an expected 900 to 1,200 per year.
- Abandonment of treatment was a major problem with 60% of children failing to complete the full course of therapy. Evidence showed that the children who abandoned treatment lived in the remote locations.

Strategic Objectives 2009 to 2013:

- Develop Southern Philippines Medical Centre into a hub of a network of satellite treatment centres;
- Improve survival rates for all children across Mindanao;
- Increase access to treatment for children across Mindanao;
- Reduce abandonment of treatment;
- Raise awareness of child cancer, its symptoms and potential curability if treated early.

Activities

- Establishment of three satellite treatment centres in district hospitals across Mindanao.
- Implementation of training programme for doctors and nurses at satellite centres.
- Development of shared care protocols between centre of excellence and satellites.
- Strengthening of parent support groups.
- Poster awareness campaign for retinoblastoma and other child cancers.

Impact of Funding to Date:

- Access to treatment has increased by over 160%. In 2012 250 children received treatment compared to 100 in 2009.
- Survival rates for diagnosed children have increased from 30% to 60% over four years (one year event free survival).
- Abandonment of treatment is now only 20% thanks to satellite treatment centres making it easier for children to receive treatment close to home.
- A local parent support group is actively raising awareness and funding locally.
- Fewer children present with advanced symptoms.

Future Development:

The development of satellite treatment centres will continue across Mindanao. Despite significant improvements over the last four years there are still major challenges. At least 70% of children with cancer in Mindanao are still not being diagnosed and three year survival rates are around 40% (as opposed to 60% one year post completion of treatment). Further work is required on protocols, drug accessibility and strengthening parent support.

Conclusion

Twinning partnerships are highly effective at transferring the skills and expertise to try to improve diagnosis, treatment and care for children with cancer in LMIC's. Healthcare professionals from both HIC's and LMIC's can benefit from the experience. Significantly, it is possible to scale-up a twinning project to encompass a region of a country or a whole country.

Conflict of interest

Joanne Hopkins and Elizabeth Burns are paid employees of World Child Cancer – a charity involved in developing twinning programmes between low and high income countries to try to improve the survival of children with Cancer in developing countries. They gain no financial benefit for writing this article. They have no other conflict of interest.

Tim Eden was a Founding Medical Trustee of World Child Cancer but works voluntarily and has no conflict of interest financially, ethically and clinically. He is a donor to the Charity's work.

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