SIOP PODC Working Group on Twinning, Collaboration and Support

Twinning Guidance

SOCIÉTÉ INTERNATIONALE D'ONCOLOGIE PÉDIATRIQUE
INTERNATIONAL SOCIETY OF PAEDIATRIC ONCOLOGY

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About this document

INTENDED READERSHIP

This document is intended as a resource for physicians, nurses, administrators and hospital and departmental leadership interested in initiating paediatric oncology twinning partnerships between high-income country institutions and low- or middle- income country institutions. In addition, it is intended to be useful to those already participating in such twinning partnerships.

FOR FURTHER INFORMATION

If you have questions, clarifications, or input/advice regarding specific elements of this document, please contact the current co-chairs of the SIOP PODC Working Group on Twinning Collaboration and Support via email addresses below. In addition, if you have significant experience in establishing or maintaining a twinning program, we welcome you to join the SIOP PODC Working Group on Twinning, Collaboration and Support by emailing the co-chairs below.

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SIOP

International Society of Paediatric Oncology (SIOP) is the only global multidisciplinary society entirely devoted to paediatric and adolescent cancer. The society has over 1,600 members worldwide including doctors, nurses, other health-care professionals, scientists and researchers. Our members are dedicated to increasing knowledge about all aspects of childhood cancer. https://siop-online.org/

Improving access to and care for children and adolescents with cancer is one of the basic goals of SIOP.

Information about SIOP Paediatric Oncology in Developing Countries (PODC) and various working groups and task forces - https://siop-online.org/podc-working-groups/

CANCER POINTE

Cancer POINTE is the name of the SIOP PODC Education and Training Working Group. POINTE's mission is to help clinicians treating children with cancer in low resource settings. POINTE provides the following:

- Information about existing twinning programs including a map of existing twinning programs, and this Twinning Guidance document - https://cancerpointe.com/twinning-map/
- Information about training courses and opportunities for clinicians treating children with cancer from low to middle income countries - https://cancerpointe.com/training/
- Access to experts from high-income countries with experience in treating children with cancer from low- and middle-income countries - https://cancerpointe.com/experts/
- Adapted treatment protocols - https://cancerpointe.com/resources/
- Resources for various clinicians - https://cancerpointe.com/protocols/

Chapter 1 Introduction

Twinning, as it applies to paediatric oncology, refers to an inter-institutional partnership between a high-income country oncology centre and a low- or middle- income country oncology centre (sometimes referred to as North-South twinning). A twinning partnership is, by definition, long-term, formalised, multidisciplinary, continuous, and has an ultimate aim of improving care and outcomes for children with cancer at the partner site.[1-4] Twinning may also refer to a similar type of partnership between two or more low-income country centres or middle- and low-income country centres located within the same region, sometimes designated as the South-South twinning model. While this guide primarily provides guidance for twinning between high-Income centres with low- or middle-income partners, many aspects of this guide can be utilized for South-South partnerships.

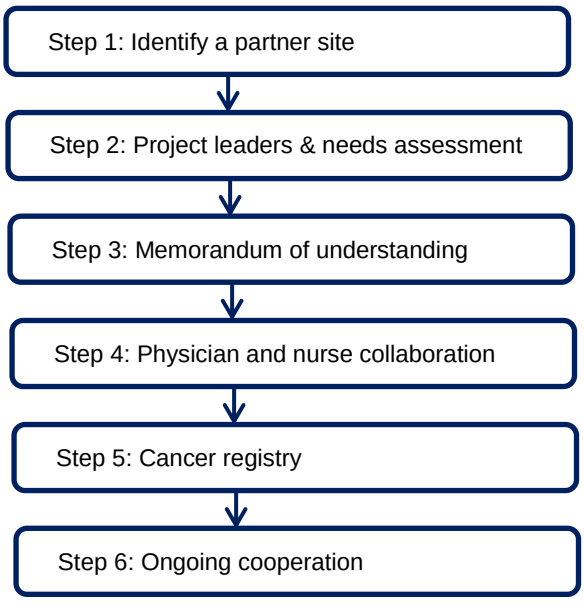
International twinning partnerships have demonstrated clear efficacy in improving the diagnosis, treatment, care and survival of children with cancer in low- and middle- income countries across a variety of settings.[3,5] While twinning programs have the demonstrated capacity to save lives at the low- and middle- income country partner site, they also provide additional benefits to the high-income country partner including opportunities for collaborative research, collaborative clinical problem-solving and educational opportunities.[2]

This document is intended to provide practical, literature-based guidance for those hoping to establish, expand or maintain a paediatric oncology twinning partnership at their institution – whether that institution is within a high, middle- or low- income country. This guidance document provides recommendations based on previous reported experiences for the establishment and maintenance of effective twinning partnerships. Areas addressed include: how to identify appropriate partners, conducting initial needs assessments, establishing a formal agreement between partner institutions, training for physicians and nurses, establishment and maintenance of cancer registries and behavioural aspects to promote ongoing success in twinning partnerships. This document is intended to provide guidance to potential twinning program leaders who can individualize use of recommendations as appropriate to their specific institution and its partners.

For those utilizing this guide who are already involved in a twinning partnership, efforts have been made to index the information in this guide in a fashion where a specific topic of interest can be easily referenced, and chapters can be utilized individually.

Process for new twinning partnerships

For those considering initiating a new twinning partnership, we recommend using this guide in the following sequence:



Step 1: Identify a partner site

Identifying a partner site: If you have a partner site identified, Chapter 2 has suggestions for aspects to consider in suitability of an institution and setting for the forming a twinning partnership. In cases where your institution is interested in a twinning partnership but does not yet have a partner site identified, please email the co-chairs of the SIOP PODC Twinning, Collaboration and Support Working Group at the addresses provided above. While this working group does not directly provide a matching service between partner sites, it does maintain a database of high-, middle- and low-income institutions seeking twinning partners and can provide this information to your institution as well as add your institution to this directory.

Step 2: Project leaders & needs assessment

Once a partner is identified, project leaders should be identified and initial meetings between the project leaders at each partner site should be held either in person or via videoconference. This is an essential first step to outline broad project goals.

Thereafter a needs assessment should be conducted (see Chapter 3 and the templated needs assessment guide provided on https://cancerpointe.com/twinning). Both partners should be involved in the needs assessment. Typically a needs assessment is conducted during a site visit to the LMIC from the HIC partner. Alternatively, the LMIC site can conduct the needs assessment and share with the HIC partner. The needs assessment is also critical early step in establishing a twinning partnership as it provides the roadmap for what areas the twinning partnership will focus on.

Step 3: Memorandum of understanding

A memorandum of understanding should be established at the outset of the twinning project (see Chapter 4 and templated MOU provided on https://cancerpointe.com/download/1983/). The MOU can take many forms from fairly informal and non-legally enforceable to a more formal document approaching a contract. Individual scenarios will call for more or less formal agreements and where questions arise we recommend consultation with your institution's internal legal counsel. Critical elements to include in the MOU include: where funding will come from, which institution will be responsible for which costs, the project's leadership, and the frequency and modality of communication between the institutions. Some sort of written mutual agreement on these matters is a highly recommended early step in the creation of a twinning partnership.

Step 4: Physician and nurse collaboration

Planning for physician and nurse collaboration and training. The importance of including nursing in the planning and development of a twinning partnership cannot be overstated. (see Chapter 6). This includes clearly identifying a group of nurses responsible for oncology patients at the LMIC partner site and a nursing collaborator(s) at the HIC site. Physician support can take the form of joint online tumour boards or patient discussions, availability for email support or more formal training efforts (see Chapter 5). What is essential initially is an outlined plan for the frequency and nature of ongoing meetings and discussions among the twinning project's participants. Additional educational initiatives can be collaboratively developed thereafter.

Step 5: Cancer registry

Establishing a cancer registry. A person or persons at the LMIC partner site should be designated to maintain a registry of oncology patients' treatment and outcomes (see Chapter 7 section: Development and Implementation of a Cancer Registry). Tracking this information is essential to measure whether the partnership is effective and where to direct ongoing efforts as the partnership develops. A basic system can be used initially and expanded as capacity develops for data management at the partner site. While Chapter 7 discusses implementation of a unit or hospital-wide EHR, this is not necessary in order to have a cancer registry and a basic registry can be implemented if capacity for EHR is not yet present.

Step 6: Ongoing cooperation

Once a twinning partnership has been established, Chapter 8 provides guidance on practices to promote positive ongoing cooperation. In addition, Chapter 9 as well as the references included for this document provide additional resources for guidance on twinning programs and links to literature describing successful twinning partnerships across a wide variety of settings.

Chapter 2 Identification of a Partner Site

Author: Nihad Salifu, MD (Korle Bu Teaching Hospital, Accra, Ghana)

Multiple factors are important in identifying centres in low- and middle- income countries (LMIC) that are most likely to be successful with assistance from twinning partnerships. Consideration should be given to the political climate in the LMIC, locally available support, the personnel to deliver progress, and hospital support for paediatric oncology development at the LMIC partner site. Specific considerations which are important for both the LMIC partner and any potential high-income country (HIC) partner include:

1. A politically stable environment that allows for free and safe movement of people. Hence the location of the LMIC centre should be in a region free of active conflict and security threats when and if possible.[3,6]
2. Governmental support for improving paediatric oncology care. The government of the LMIC centre and/or local government must recognize a deficiency in care for paediatric cancer patients and demonstrate an interest and commitment to providing resources and support toward its improvement.[7,8]
3. The full support of the local hospital leadership/administration as well as health planners and health ministries is key prior to proceeding with a planned twinning partnership. Without hospital-level support for a paediatric oncology twinning program, success and sustainability are significantly less likely.[3,8]
4. A relationship with a local not-for-profit foundation or NGO interested in paediatric cancer care. This can provide a means for sustainable fundraising and management of financial resources, provide sources of additional support for patient services, and ensure program continuance regardless of the stability of the local government.[7,8]
5. A trained paediatric oncologist or paediatrician with full commitment to paediatric oncology who will serve as director of the twinning program. This is absolutely critical to a successful twinning program and this leader needs to be identified prior to initiation of any twinning arrangement.[3,7,8]
6. A core team and hospital unit focused on paediatric oncology at the LMIC partner site. Clearly identifying the primary members of this team who will be dedicated to the paediatric oncology twinning program is crucial.[3]
7. A preliminary plan outlining realistic goals with timelines based on an initial needs assessment (refer to Chapter 3). This plan must be written by the team in the LMIC, then agreed upon with the twinning partner. For long term sustainability the LMIC centre must “own” the project, not the HIC partner.
8. Local community mobilization (friends/parents/influential members of society) for advocacy and fundraising within the LMIC.[3,8]
9. Development of a formal link between the LMIC and one or more established oncology unit(s) in high income countries (refer to section on Memorandum of Understanding).
10. On the high-income centre side of the partnership, a paediatric oncologist with long-term commitment to the partnership is essential. Oncology nursing commitment at the HIC site is highly important. A supportive hospital administration is needed. Some initial funding from the HIC centre can also be a helpful component.

Chapter 3 Conducting an Initial Needs Assessment

Author: Kevin R. Schwartz, MD (Massachusetts General Hospital, Boston, MA)

An initial survey of existent capabilities and needs of the LMIC partner site is a critical first step in establishing where to allocate financial and human resources for a strategic twinning plan.[9-11] An initial needs assessment should, at a minimum, incorporate evaluating the following at the LMIC site[7,12,13]:

1. Current patient demographics
2. Personnel
3. Facilities
4. Diagnostics (Laboratory, Pathology, Radiology)
5. Blood Bank
6. Access to Medications (Chemotherapy, Supportive and Palliative)
7. Infection Control Measures
8. Cancer Registry/Database
9. Financial Resources
10. Supportive Care
11. Practice Guidelines in place

Specific aspects of each component to be evaluated are detailed below and a suggested template for needs assessment can be found on the Twinning page on https://cancerpointe.com/twinning-map/.

1. Current Patient Demographics

Information regarding the patient population and disease outcomes should be collected, including:

- Number of patients treated annually (e.g. over the past 2-3 years)
- Age range of treated patients
- Number of new diagnoses annually by tumour type and stage
- Percentage of patients offered curative treatment
- Percentage of families who refuse and/or subsequently abandon treatment
- Patient outcomes by tumour type over the past 2-3 years (number of new cases, number of patients alive after first remission, number of patients with relapse, number of patients deceased, number of deaths attributed to infection or other toxicities, number of patients who abandoned therapy, number of deaths within 30 days of diagnosis)

Where a cancer registry or database has not been in place and the above information is not available, an effort should be made to manually obtain this data from existing clinical charts and plans should be set to systematically collect this information going forward (refer to Cancer Registry/Database section)

Because abandonment or refusal of therapy can be a major contributor to poor outcomes in paediatric oncology care in LMIC, an effort should be made to identify factors potentially contributing to abandonment.[14]

Reasons for abandonment and refusal that may be queried include:

- parents do not believe a cure is possible
- parents cannot afford therapy costs

- parents/guardians cannot cope with family disruption and loss of family income
- family cannot afford to travel
- other factors (stigma of having a child with cancer)
- preference for locally affordable traditional therapies
- Other factors

Where abandonment is significantly present, efforts should be made to ascertain what interventions are underway at the LMIC partner to mitigate this. These efforts can involve the LMIC centre partners detailing common reasons for abandonment (if known) or surveying patients and families regarding potential causes of abandonment.

As malnutrition has specific consequences for oncology care, an effort should be made to ascertain the frequency of malnutrition in paediatric oncology patients treated at the centre in initial demographic data collection.[15,16] This information should be assessed and recorded by the LMIC centre partners either in collaboration with the HIC partner or independently depending on available data and personnel.

2. Personnel

A complete assessment of the staff available to care for paediatric oncology patients should be undertaken and an effort should be made to understand what portion of each provider's time is dedicated to paediatric oncology care rather than other responsibilities. In order to fully understand the personnel capacities of the centre, it is useful to gather information about a wide variety of personnel involved in the care of the paediatric oncology patient, including:

- paediatric oncologists
- general paediatricians
- paediatric surgeons
- pathologists
- radiation oncologists
- radiologists
- paediatric intensivists
- residents/fellows
- nurses with specific training in paediatric oncology
- other nurses
- pharmacists
- nutritionists
- social workers
- physiotherapists
- psychologists
- child life specialists
- Others (e.g. teachers if schooling is available in the unit)

3. Education and Training

In addition to an assessment of the number and availability of each member of the medical staff, an assessment of Continuing Professional Development/In House Training available to the staff should be undertaken, including an assessment of:

- whether multidisciplinary ward rounds/meetings are conducted and with what frequency
- whether a regularly scheduled tumour board is in place and with what frequency
- whether regular teaching sessions in paediatric oncology exist for physicians and/or nurses and how frequently

4. Facilities

Current facilities and infrastructure at the LMIC partner site should be assessed including:

- whether there is a dedicated paediatric oncology ward or whether patients are bedded on a general paediatric ward
- whether the ward has individual rooms, an open ward design, or a mixture
- current bed capacity dedicated for paediatric oncology
- how many inpatients sleep in the same room
- whether there are any isolation rooms
- availability of reliable and consistent electricity supplies and whether a backup generator is available
- availability of clean water for handwashing and other use, and of hand cleaning gel
- availability of housekeeping services
- whether there is a guest house or shelter where outpatients and parents can stay when receiving treatment.
- whether there are outpatient clinic facilities with capability to give outpatient infusions
- whether there is access to an ICU and what its capabilities are
- whether there is access to radiotherapy in the hospital, city, country, or abroad

5. Diagnostics (Laboratory, Pathology, Radiology)

The on campus and off campus diagnostic capabilities of the LMIC partner should be understood, including:

Laboratory Services

- turn-around times and availability of complete blood counts and films, bio- chemistry tests of blood, renal and liver function, microbiology cultures (bacterial, fungal, viral).
- ability to measure antibiotic and antineoplastic (e.g. methotrexate) levels

Pathology services

- Availability of pathology services to diagnose malignancies and assessment of whether these are run in house or sent elsewhere (to public or private labs) including: Surgical Pathology, Bone Marrow Morphology, Cytogenetics, Immuno-phenotyping, Immunohistochemistry and CSF cytospin.

Radiology

- Extent of available imaging modalities (X-rays, ultrasonography, CT, MRI) and experienced radiologists available to interpret them in a timely fashion.

6. Blood bank

The following information should be obtained regarding blood banking services:

- availability of whole blood, PRBCs, platelets, FFP, cryoprecipitate
- how long it takes to receive blood products for emergency transfusions
- whether blood is stored at the site of the hospital or elsewhere
- policy for obtaining blood or blood products

7. Access to Medications (Chemotherapy, Supportive and Palliative)

Inconsistent medicine supply chains are a common challenge faced by many LMIC oncology centers.[17] As such, an understanding of medication supply issues is an important component of the initial assessment. Information to be obtained should include:

- whether there are stock outs of chemotherapy, how often and of which medicines.
- who pays for the drugs needed to treat cancer (for supportive, curative and palliative care): government vs. hospital vs. local foundation vs. twinning partnership vs patient's family
- the most common drugs that are difficult to access
- who prepares IV chemotherapy for administration (physician vs. nurse vs. pharmacist)
- whether there is there a laminar flow hood for preparation of chemotherapy
- where chemotherapy agents are stored
- whether there is a means to subsidize chemotherapy costs for patients.
- whether there is access to palliative care medications such as opiates
- whether there is access to antibiotics and which ones.

8. Infection Control

An attempt to understand current infection control measures in place at the LMIC centre should be made, including:

- whether there is a formal infection control program in place
- whether soap and hand sanitizers are consistently filled and easily available
- whether there is formal staff training in infection control and any surveillance of staff compliance

9. Cancer Registry/Database

Effective data collection represents a key step in improving paediatric oncology outcomes, as such, an understanding of the existent data management practices and registry present at the LMIC partner-site is extremely important at the outset of a twinning partnership.[18] Assessment of the data registry should include (refer to Establishment of Cancer Registry/Database section for further detail)

- Understanding how new cancer cases and their outcomes are presently registered (paper log book vs. MS Excel based database vs. other databases vs. a national population–based cancer register for childhood cancer)
- understanding who is responsible for maintaining the patient database (physicians vs. nurses vs. dedicated data manager)
- assessing whether there is reliable and consistent internet access
- cataloguing what data is consistently collected on each patient

9. Financial Resources

An assessment of where payment for paediatric oncology services derives is a key component of the initial needs assessment. Evaluation should include:

- Documenting who provides payment for the treatment of patients (parents, government, insurance, local foundation) and in what proportions if costs are shared
- Ascertaining whether a local non-profit foundation supports the paediatric oncology program at the LMIC site, and /or external funding is available

10. Supportive care

An overview of supportive services available to patients and families at the LMIC partner should include assessing:

- whether there is a parent support group for the unit and if so what provision does it give to the unit
- whether support is provided for transportation to the centre and by whom
- whether support is provided for nutrition with supplements for families who cannot afford this.
- whether palliative care services are available in the hospital and in the community on discharge of a patient
- whether procedures such as Lumbar Puncture and Bone Marrow Biopsy/Aspirate are performed with or without sedation/anaesthesia

11. Protocols/Practice Guidelines

The existence of clinical guidelines for common conditions associated with cancer diagnosis and treatment should be assessed, including inquiring about guidelines for:

- fever and neutropenia
- blood product transfusions
- nausea and vomiting
- pain control

- oral care
- hand washing/hygiene

Chapter 4 Memorandum of Understanding (MOU)

Author: Bernard Anim, MD (Harvard School of Public Health, Boston, MA)

Introduction

Written formalization of a twinning partnership engenders heightened commitment on the part of all involved Parties, provides a guiding framework for the intended ongoing activities, and creates a ready-to-reference resource for internal and external stakeholders. Commonly in twinning partnerships, this formalization in writing takes the form of a Memorandum of Understanding (MOU) which can be developed and agreed upon by both institutions in the twinning partnership.

What is an MOU?

While no formal definition exists for an MOU, it is essentially defined by its spirit. It may be considered to be a written document that formalizes a bilateral or multilateral partnership in either a legally binding or non-legally binding manner. It expresses a convergence of will between the Parties involved and indicates an intended common line of action.

Sample MOU

A sample MOU can be downloaded here: https://cancerpointe.com/download/1983/

This sample MOU is meant to serve only as a template as different institutions will require different components in their agreements. If utilized, it should be adapted to reflect the specific needs and regulations of the parties utilizing it. We suggest including some combination of the below elements in most MOUs created between twinning partners.

MOU versus other formal agreements

An MOU is more formal than a verbal or implied agreement and is most often used in cases where the Parties are not desirous of creating a more legally enforceable agreement such as a contract or are unable to do so (because of different court/legal systems across international borders for example). Consequently, MOUs are best suited for arrangements underpinned by high levels of inter-party trust and have at their core a commitment to resolving any disagreements between parties via negotiation first and foremost rather than legal action.

While an MOU may not be legally binding in its entirety, the breach of some of its provisions may constitute grounds for legal liability and lead to discontinuation of the partnership. Statements contained within the MOU may help protect institutions from specific liabilities that may be incurred in the course of a twinning partnership.

Purpose

As a form of formalized agreement, an MOU covers a number of areas pertinent to a collaborative undertaking and serves to achieve important objectives critical to the success of a partnership.

A well-developed MOU will serve as a:

- formal commitment to the partnership by all Parties

- pronouncement of the congruence of mission, values, and strategy
- a statement of the purpose and goals of the partnership

The MOU should clearly define lines of authority or responsibility and clarify cooperative procedures. These definitions enhance the effective use of unilateral or collective resources and assure the elimination of the duplication of activities.

Negotiating and developing an MOU

In the spirit of cooperation, an MOU should be negotiated and jointly developed, with opportunities for input by all Parties in the partnership. This requires a good mutual understanding of each party's mission and objectives.

Several over-arching principles may guide the negotiation and development of an MOU:

- A mutually shared desire by all Parties to enter into an MOU, with equal commitment to working together, should exist
- No MOU should be developed that conflicts with any existing arrangements between the Parties, nor with any arrangements either party might have with other organizations;
- An MOU should be clear and unambiguous in language, and its structure and content should permit easy reviewing and updating;
- An MOU is a 'living' document and should include provisions for how it can be reviewed and updated and with what frequency.
- The development of an MOU should be guided by legal, financial or other relevant expertise, as may be necessary, with a goal to forestall creating provisions that may have unintended implications or produce unreasonable expectations.

Types and formats

There are no standardized guidelines on the form an MOU should take. The particular circumstances of a partnership will determine which content should be included in its guiding MOU and what provisions should be addressed. In some instances, an MOU may be developed that focuses more on operational or procedural matters than MOUs traditionally address. The content below is commonly included within an MOU utilized in a paediatric oncology twinning partnership:

Content

The following content list is provided as a generic guide to assist the development of an MOU. The use of this guide, together with the sample MOU available on the twinning page of cancerpointe.org, should permit the development of an appropriate and effective MOU that fits the needs of a given partnership.

1. Identification of Parties

A formal identification of the Parties to the agreement and a broad description of their relationships to each other should be made

2. Background

Broad statements defining the context and vision of the partnership should be made. A brief summary of the circumstances leading to the creation of the partnership might be included here.

3. Purpose of the partnership

The expected outcomes of the partnership, including intended benefits to internal and external stakeholders, should be clearly articulated.

4. Scope of the MOU

Statements should be made about the boundaries of the MOU. Consideration should be given to any boundaries that are defined by existing MOUs and the scope carefully described to ensure there is no overlap or contradiction. Some of the areas to be addressed here might include the circumstances under which the MOU may or may not apply, whether it applies across the whole of each organization or just a part, and whether the provisions only apply at certain times of year, in particular locations only, or for particular activities only.

5. Legal context

A clear statement should be made on the extent to which the MOU is legally binding. The status of the MOU in relation to other existing agreements should also be mentioned; this ensures that the responsibilities outlined in the MOU are compatible with the mandate and duties of each agency.

6. Definition of terms

A listing of agreed definitions and interpretation of relevant terminology may be provided.

7. Terms of operation of the partnership

The terms of operation of the partnership should be defined to include the following:

a) Term/duration of the partnership;
b) Waivers and rights involved in the MOU to make compensation claims (related to the execution of the MOU) against one another;
c) Intellectual property provisions;
d) Privacy and confidentiality provisions;
e) External visibility of the partnership and/or its project(s); and
f) Methods for transferring funds (if applicable).
g) Dispute resolution, including (or excluding) legal actions, negotiations, consultations, or executive actions;
h) Partnership termination provisions; and
i) MOU review and amendment processes

8. Governance infrastructure

There should be a clear definition of the governance infrastructure of the partnership, including an unambiguous delineation of the authorities and responsibilities of persons nominated to handle technical, managerial, administrative and other aspects of the partnership as well as procedures for replacing leadership personnel/required notice of leaves.

9. Joint undertakings and responsibilities

Statements describing the responsibilities and actions of each Party should be made to include the following:

a) A description of the cooperative activities of each Party under the MOU;
b) A description of any resources exchange arrangement;
c) Statements on timing, including relevant timelines, milestones and agreed frequency of cooperative activities;
d) Protocols for communicating between the Parties; and
e) Methodologies and processes for monitoring, evaluation, and learning

10. Official endorsement by each Party

The MOU should be formally signed by appropriately delegated representatives of each Party. All Parties should retain copies of the formally endorsed MOU for their records.

11. Additional annexes as required

Material that provide greater detail on relevant matters, such as agreed work plans, milestones, timelines, budgetary matters (if required), etc., may be added. The MOU should contain a provision that stipulates that *the annexes form an integral part of the MOU.* If there is a need to change the annexes, this shall be done in accordance with the amendment provisions contained in the main body of the MOU.

Chapter 5 Physician Training and Support

Author: Julie Cayrol, MD (Royal Children's Hospital Foundation, Melbourne, Australia)

Introduction

Physician training is an essential aspect of twinning programs, facilitating the long-term sustainability of a childhood cancer program. It allows transfer of knowledge, organizational skills and management responsibilities to the local professionals, and helps to increase autonomy and self-reliance. Capacity-building is an important aspect of any twinning program. Partnerships should aim to build independent paediatric cancer units rather than ones that rely long-term on partners from high income countries (HICs).

At the centre of the twinning program there must be a paediatric oncologist or a paediatrician with a dedicated interest in Oncology. Good relationships between the leader and team in the LMIC and the volunteering leader and team from the HIC(s) is critical for success. One of the responsibilities of the HIC partner is to ensure ongoing education and support of the staff members in the unit, and this should include nurses (refer to Nursing Training and Support section) as well as rotating junior medical staff, who are often the first point of contact for patients.

Paediatric Oncology units also need the availability of other specialists including pathologists, haematologists, radiologists, surgeons, infectious disease specialists, microbiologists, pharmacists and social workers and /or psychologists so that children can be diagnosed correctly and can receive the best care and treatment. Gradually such a team must be created and have the capacity and desire to help the oncology team.

Education about the needs of children with cancer and providing support should also target government, Ministries of Health and directors/managers of hospitals if the twinning is to be successful. Families and parent groups should be a key component of the development of the service.

1. Training Models

a) In-country training

In-country training is often described as the most effective way to deliver teaching, as it happens in the local context and with the available resources there and can be easily implemented by the local staff. It can have both a theoretical and a more practical approach, based on case discussions and patient reviews.

Often, twinning partners will chose to have a theoretical introduction to childhood cancer or its specificities, with seminars and workshops, at the central level but also at the provincial level, as a way to initiate staff and cover a broad range of topics such as initial diagnosis of paediatric cancers, management of oncologic emergencies, supportive and palliative care and reach out to a large number of physicians in different parts of the country, depending on the size and geographical distribution of the country.[2,4] They are a good way to target a varied audience that can include general paediatricians or rotating residents and junior staff. Seminars can also cover specific oncology topics that a paediatric unit would like covered, such as Neuro-oncology.[19]

i) Bedside teaching

However, with this theoretical teaching style, and despite being "on the ground", knowledge retention and practical application can be difficult and there is a risk of losing acquired knowledge. Therefore, partners in HIC are encouraged to favour more practical teaching approaches, such as on-site visits, where time allows to review patients conjointly and discuss organizational concerns that do not always arise in workshops. This creates a model of mentorship and supervision which has more impact on changing behaviour and implementing different practices. This also presents an opportunity to understand the local culture and habits, the local staff, medical practices, resources available, as well as barriers and enablers.[20]

Training in supportive care remains one of the main focuses of physician training and support, as high toxicity rates in the early phases of treatment can be reduced with improvements in supportive care. This includes: early

detection and management of chemotherapy complications, management of sepsis and infections, detection and management of malnutrition and management of pre-existing co-morbidities. Training needs to be directed to both senior physicians as well as residents, junior staff and nursing staff.

ii) Training local teachers

An additional on-site training model is the "training of trainer" model, which is used in large public health interventions for medical education, mainly when needing to roll out a program to smaller provincial/district hospitals or wider teams. While paediatric oncology programs are often centralized in large hospitals in capital cities, this may be a model that is useful for teaching early warning signs, supportive care, palliative care or in the future when current programs expand to smaller cities.[21]

Local universities have a role in integrating paediatric oncology curricula into their undergraduate and postgraduate training and in "pre-service" training, to ensure ongoing education of newly graduated doctors for the future.

b) Training abroad

Training in high-income countries through scholarships, exchanges or fellowships may supplement local training by providing an example of quality standard of care practices. However, the resources available are often very different and some practices may not be applicable to the LIC.[2] Short training courses for key issues with a contract to return home can be useful. If an arrangement is made for longer periods (usually 1-2 years maximum) then there must be a contract for the trainee to return to the home country bringing back increased knowledge and competence. On return there must be a position available noting the increased status of the trainee.

Some fellowships have been created in partnership with HIC to deliver training in a LMIC over 2-3 years to physicians from neighbouring countries, as for example the 3 year post-doctoral haematology/oncology fellowship at Unidad Nacional de Oncologia Pediatrica (UNOP, Guatemala) accredited by the Guatemala Universidad Francisco Marroquin School of Medicine, following a so-called "south to south twinning" model. [8] There is also a new fellowship initiative that has been created in Accra for West Africa and the first two fellows started in April 2019 as well as other examples.

c) Continuing education and support

This is one of the essential aspects of all physician training in twinning programs. Continuing education through case discussions and mentorship is a more effective way of mentoring and building capacity. It can be done during site visits but also using the telemedicine model, via telephone, emails, teleconferences, etc.

Regular contact via telephone, email and videoconference, is important to building a trusting relationship, and is a good platform to discuss patients but also organizational matters, research questions and results, and to share resources. These correspondences require an internet connection but no other specific costly hardware or software. Qaddoumi et al described a lengthy email exchange between the King Hussein Cancer Centre in Jordan and the Sick Kids Hospital Toronto, that provided continuing medical education, with a clear impact on clinical care, including the reduction in use of radiotherapy in patients with low grade glioma, but also improved quality assurance, while providing an emphasis on teamwork and multidisciplinary care.[19]

Teleconferences and web-based meetings to hold multidisciplinary meetings to discuss all initial diagnoses and complex cases are one of the main clinical activities in a twinning program and provide the basis for supervision and ongoing clinical education.[4] Ideally these are accompanied by written documentation of these conferences that can then be circulated for future reference.[22]

d) Registries and databases for training

Registries and databases can also be used for provision of feedback on clinical care, to review outcomes in order to potentially modify protocols and treatment approaches, and also to promote research.[4,22,23]

Standardised inpatient and outpatient documentation clinical forms or clinical decision-making tools have been used to guide and support management of patients and prompt quality of care.[23] More broadly, promoting detailed documentation and ensuring records are safely kept, not only facilitates patient care but also allows for review of patient records to analyse results.

e) Adapted protocols and training

Adapting protocols locally and creating guidelines with local physicians is an opportunity to engage the staff in their own local practices and also creates research opportunities. Ideally these protocols would be reviewed and accepted by the international paediatric oncology community. Some examples of protocols that have been led and adapted directly by local team members with the support of their HIC partners, include the Dutch Indonesian Wijaya Kusuma-ALL-2000 protocol which involved Indonesian staff and where different research questions formed the basis of PhD studies of Indonesian and Dutch staff[2]; the Recife ALL protocol (RE-ALL-05) which aimed to reduce treatment-related toxicity and identify patients with a good initial response who could benefit from less intensive therapy.[22] In other programs, supportive care and fluid management guidelines were created locally with the support of HIC partners.[20,23]

f) Online resources

There are various online resources available for physician education, namely Cure4kids website which is open access, including St. Jude's www.cure4kids.org and SIOP's cancerpointe.com. Some platforms also allow users to create groups and folders to share articles and protocols safely.

g) Research opportunities

An additional benefit of partner training support is that it can lead to developing experience in research. Several twinning groups have reported their outcomes on different adapted protocols, as well as other aspects of treatment such as rates and causes of abandonment and toxic deaths.[2] This provides a solid initiation to research, while stimulating a research interest and promoting data-informed clinical decision making.[22]

Chapter 6 Nursing Training and Support

Author: Elizabeth Sniderman, MSN, RN, CPNP-AC (St. Jude Children's Research Hospital, Memphis, TN)

Introduction

Nurses represent the largest group of health care providers globally, and adequate training and support of high-quality, specialized paediatric oncology nursing is vital in improving outcomes for children with cancer in LMICs. Adequate nurse staffing and nurse education/and training has been proven to contribute to shorter hospital stays, decreased complications, and decreased mortality in studies in HICs.[24] The WHO has acknowledged and recommended the key role of nurses as front-line clinicians that are critical for positive patient outcomes, but that globally, nurses lack good training, and are not well deployed.[25] Most hospitals in LMICS are very poorly staffed. Hospitals participating in twinning partnerships have a responsibility to assess nursing capacity in their partner sites, and advocate for a scale-up of nursing education, staffing, and resources for safe and evidence-based care.

Baseline standards for paediatric oncology nursing in low to middle income countries

The SIOP Paediatric Oncology in Developing Countries Nursing working group has developed a set of baseline standards for the provision of nursing care of children with cancer in LMICs. These standards represent a group of evidence-based suggestions for the nursing workforce, which can be used to help assess current nursing capacity, identify areas for improvement and training, and to advocate for additional resources. [25,26]

These baseline nursing standards can be accessed online here:

https://siop-online.org/baseline-nursing-standards/

The six standards are:

1. **Staffing based on patient acuity**, with patient ratios of 1 nurse:5 patients in paediatric oncology units, and 1:2 in critical care and transplant units. Specially trained paediatric oncology nurses should be maintained on the unit and not rotated.
2. **Formalised Paediatric oncology orientation** for new nurses, including specific learning objectives, theoretical and clinical skills training, and protected time with a skilled preceptor prior to providing unsupervised care.
3. **Continued education and training** for nurses of at least 10 hours per year.
4. **Nurses should be acknowledged as core members of the multidisciplinary team**, and should be included in patient rounds and family meetings discussing diagnosis or treatment information.
5. **Resources for safe nursing care** must be made available, and nurses should not prepare chemotherapy unless a pharmacist is not available and safety equipment has been provided.
6. Evidence-based paediatric nursing policies and procedures should guide nursing care.

The following are specific suggestions for utilizing the baseline standards to guide nursing training and support in twinning partnerships:

Staffing

The standards recommend a nurse: patient ratio of 1:5 in general paediatric oncology wards, and 1:2 in transplant or critical care units.

- Twinning partners should assess:

- Staffing ratios, considering ratios of various shifts
- The mix of skill level of the nursing staff (e.g. professional vs. technical nurses, nursing aides, etc.)
- Whether nurses are required to rotate throughout the hospital or specially trained and maintained on the paediatric oncology unit

If it is ascertained that this standard is not maintained, twinning partners should negotiate and advocate with hospital leadership to increase nurse staffing resources to move towards the baseline recommendations. In some examples, twinning partners have been able to support nursing personnel, either through direct support or via a local foundation.[27] Providing evidence that nurse staffing is directly linked to patient outcomes is critical in persuading hospital administration to increase nursing human resources.

Furthermore, twinning partners must advocate for the retention of highly specialized paediatric oncology nurses on the paediatric oncology units, and work with the local nurses to identify those who are interested in dedicating themselves to the paediatric oncology ward.

2. Orientation program

The baseline standards recommend a formal orientation program for all new nurses to the paediatric oncology unit, which should include two weeks of theory and clinical skills training, followed by 3-4 weeks with an experienced nurse preceptor prior to independent patient care. Suggested content to be covered in the orientation program includes: review of paediatric cancers, chemotherapy administration and side effects management, care of peripheral and central venous access devices, infection prevention and control measures, blood product administration, early detection and management of oncologic emergencies, including neutropenic sepsis, pain assessment and management, nutrition, patient and family education, and palliative care.

Assessment of partner sites should include:

- Presence and length of orientation
- Presence of specific, measurable learning objectives
- Content included in theory/skills training
- Presence and length of attachment with a preceptor on the unit prior to independent patient care

Nurses from HIC partner sites can be heavily involved in assisting the local nurses in creating a paediatric oncology nursing orientation program, as most (if not all) hospitals in HICs have already developed such orientation programs. Nurses from HIC partner sites can also serve as content experts for the orientation modules, as applicable.

One model for paediatric oncology nursing specialized education that has been particularly successful is the train-the-trainer nurse educator approach.[27-29] The creation of a dedicated position for educating nurses may be unfamiliar to hospital leaders in LMICs, and may require advocacy and support from the twinning partners. The nurse educator should be trained in adult education principles and supported in creating and implementing an orientation program that will be taught to all new paediatric oncology nurses. Although it is ideal to train nurses in-country, twinning partners may be able to have a substantial impact on the education of all nurses in an institution by training a nurse educator at a designated training centre or international fellowship, or at their own institution.

3. Continuing Education

At least ten hours per nurse annually in paediatric oncology nursing skills and knowledge is recommended by the baseline standards.

Assessment of partner sites should include assessment of opportunities for continuing education, including:

- Provision of weekly or monthly onsite education sessions
- Access to online education resources
- Access to paediatric and oncology nursing journals
- Support for attendance of local, regional, or international paediatric oncology nursing conferences

- Dedicated time for pursuing continuing education activities
- Tracking mechanism for nurses' continuing education activities and hours

Nurses at HIC partner sites can help support continuing education activities through provision of monthly online education and distance learning tools, or support for journal subscriptions or journal clubs.[29] Twinning partners can also consider supporting nurses to attend conferences through scholarships; advocacy for supporting nurses' time away from work by hospital leadership will be important as well. Additionally, the development of annual nursing workshops with various continuing education topics can be supported by twinning partners. As with all education support, consideration must be made for the local situation, such as cancers commonly seen, equipment and medications commonly used, and the role of nurses within the local social and cultural context.[29]

4. Multi-disciplinary Teamwork

Nurses should be integrated as core members of the multi-disciplinary team, who contribute through front-line care delivery, patient and family education, early detection, treatment administration and identification of treatment complications, provision of palliative care, and collaboration in clinical research.[30]

Assessment should include:

- Nurses' participation in daily rounds
- Nurses' presence at family meetings, diagnosis/prognosis/treatment plan discussions
- Nurses' comfort at reviewing and questioning inappropriate physician orders

Nurse and physician team members from twinning sites in HIC are in an opportune position to advocate for nursing participation in daily rounds and interdisciplinary meetings; administrative support for these changes should be obtained.[27] Modelling of effective communication, mutual respect, and partnerships between physicians and nurses by HIC partners is an effective way to begin the shift towards including nurses as important members of the multidisciplinary team, and there is evidence that physicians from LMICs who have received training in HICs have returned home to integrate nurses in rounds, family conferences, and treatment decisions.[25]

5. Resources for Safe Care

Access to resources such as IV pumps, personal protective equipment (PPE) and isolation supplies, and hand hygiene stations and supplies are imperative for the provision of high-quality nursing care. Chemotherapy preparation should not be under the scope of nursing practice, unless a trained pharmacist is not available. If a nurse must prepare chemotherapy, appropriate training, PPE and a biosafety cabinet level 2 must be available and used properly to protect nurses.[30]

Assessment of partner sites should include:

- Availability of PPE for isolation: gloves, masks, gowns
- Availability of chemotherapy PPE: chemotherapy safe gloves, non-permeable gowns, shoe covers, masks with face shields
- If nurses prepare chemotherapy, training must be provided and the availability of PPE (as above, plus a respirator) and a functioning biosafety cabinet level 2
- Presence and functioning of hand hygiene stations and supplies
- Other safe nursing resources, including but not limited to: IV pumps, sharps containers, safety needles, chemotherapy spill kits, hazardous waste management, etc.

Twinning partners should take an active role in advocating for the availability of safe resources, including providing examples of resources used in their own institution that could be purchased or donated in-kind, depending on the twinning relationship. Education of hospital leadership on the importance of safe handling of hazardous drugs may be undertaken by nurses, pharmacists, or physicians from HIC partner sites; training of nurses handling chemotherapy on safe handling can also be supported by nurses and pharmacists.

6. Evidence-based policies and procedures

The delivery of high-quality nursing care should be guided by evidence-based policies and procedures. Nurses can be very effective in participating in the development of resource-appropriate best practice guidelines.[30] Further, funding for locally directed nursing research should be encouraged in order to provide evidence for the creation of these policies and procedures.

Assessment of partner sites should include:

- Presence of nursing policies and procedures to guide nursing care
- Access to nursing journal and textbooks to inform evidence-based nursing policies and procedures
- Nurses' participation in research and any nurse-led research activities

Support for the development of nursing policies and procedures by twinning partners may be necessary in sites without established policies and procedures. This may include sharing of the policies and procedures from the twinning institute; or assisting in auditing and updating policies and procedures according to the latest evidence. Nurses in LMICs may not have any training in evidence-based practice; partner sites can support them by providing access to education and training in evidence-based practice.

Many twinning partners have experienced nurse researchers; these researchers should identify nurses to partner with at the twinning site in evaluating all quality improvement or other nursing projects that are undertaken at the site. There is a scarcity of literature on paediatric oncology nursing best practices in LMICs, despite many successful twinning partnerships, and nurses can make pivotal contributions in translating research to evidence-based, resource-appropriate best practices.[30]

Chapter 7 Electronic Health Records and Cancer Registry

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Background

As the burden of cancer increases in developing countries, information from cancer registries has become vital for assessment of the burden and epidemiology of cancer, and for planning and implementing cancer prevention and control initiatives. However population-based cancer registration is often neglected in favour of higher health care spending priorities, and information on cancer epidemiology and outcomes in LMICs is subsequently scarce and unreliable, with only 2-10% of the population in LMICs covered by cancer registries of adequate quality.[31] This hinders the development and limits the efficacy of cancer control initiatives such as twinning programs.

Health records are an essential part of providing care for children with cancer. They enable health care providers to achieve continuity of care, keep track of the complex treatment protocols and milestones, accurately follow up disease progression and response to treatment, as well as reduce chemotherapy side effects and drug reactions.

Electronic health records (EHRs) have several advantages over traditional paper-based records: They are less liable to damage and loss, can be accessed by more than one provider simultaneously, help reduce loss to follow up, and facilitate data collection for population surveys and research. While EHRs have become the standard of care in the developed world, they are much less commonly employed in LMICs.[32]

Establishing an electronic records system is one of the most impactful activities a twinning program can include and has the potential to benefit both oncology and non-oncology patients. Where possible, a hospital-wide EHR implementation should be encouraged and supported. For those centres not yet able to implement full-scale electronic health records, specific solutions for oncology data collection do exist and are discussed below. Ultimately the development of complete ascertainment of incidence and outcome in each hospital is desired. Creation of shared care networks in each LMIC will lead to an accurate population-based cancer registration for children.

Approach to EHR Implementation

1. Evaluation of data management practices at twinning site

Evaluation of the current medical records system in the LMIC partner site should be carried out during the initial needs assessment activities. This includes assessment of presence and use of health records in the hospital, and whether they are paper-based or electronic. General considerations in reviewing the existent record-keeping practices include:

- **Study the current patient record-keeping practices:**

  What kind of data is being recorded?

  Is there a well-defined record stewardship and responsibility structure in place?

- **Evaluate whether medical records are used effectively and meaningfully for patient care:**

  Are records kept consistently up to date? Who is responsible for a patient's record maintenance?

  Does a patient record contain data that is sufficient and conducive to providing a good standard of care for children with cancer?

Is critical data (for example, blood types, drug allergies, chemotherapy dosage dates) easily identifiable and consistently captured?

Is the data being collected at a sufficient resolution to use in research?

- **Evaluate Infrastructure, personnel and resources needed for an EHR system upkeep:**

  Is there stable electricity supply and consistent internet access?

  Does the twinning site have local technical support personnel, preferably experienced with operating and maintaining computer systems?

Design and implementation of an EHR system at the twinning site

A. Interim measures

Setting up an EHR system is a time-consuming process. During the planning phase, some benefit to the clinical care quality and outcomes can still be achieved by implementing a basic electronic record-keeping system using common office applications to store patient information in spreadsheets or databases on a networked drive, which can be accessed by computers within the hospital connected to the same network. This method ensures ease of access to patient data and realizes some of the gains of using EHR systems over paper records, but it must have good security. Furthermore, this method facilitates importing data into an EHR system once it has been deployed.

For such an interim system, data should be kept in a rigidly structured and defined format. An example is presented in the “Data quality and record content” section of this document.

B. EHR: Buy or Build?

One of the first questions when discussing the acquisition of an EHR system is whether an existing solution can be acquired (commercial or open source), or if it should be built from scratch. This initial choice is the most important, as history has shown that a hospital’s first EHR system often becomes its permanent system and changing it after being in use for a few years is a costly and complicated process. Therefore, it is imperative that the chosen EHR system be scalable, follows international design standards, can integrate with other hospital systems (pharmacy, imaging, accounting and supply chain), and is actively supported with regular maintenance updates.

A multitude of EHR systems exist, including both commercial products or Open-Source/research projects. There are many factors to consider when choosing between a commercial and free alternative.

Commercial solutions

Commercial solutions are provided by vendors (most notable of which are EPIC and Cerner PowerChart), are costly to purchase and set up, and require a sizable investment in hardware, server infrastructure and personnel training. Commercial systems are often “walled gardens” where only the vendor can make modifications, customizations or provides updates. Most commercial systems lack interoperability as a standard, which hinders data exchange between hospitals using different systems.[33]

Open-source solutions

Open-source solutions, in contrast, are software packages that have been made freely available for use, and where the authors have made the source code available for the community to download and modify with no restrictions. Examples include VistA, POND4Kids, OpenEMR, Stre@mline, OpenMRS, and many others that have proven to be valid, accessible and, perhaps most importantly, customizable: Systems that are customizable can be developed or modified by users in LMICs to better suit local needs and workflows.[32,34,35]

While Open-source systems may seem like the logical choice, it must be taken into consideration that open-source EHR systems are built and supported by the user community, and do not come with the kind of technical support that is seen with commercial products. As such, it will be imperative to develop the local capacity to provide sustainable maintenance and customization of the EHR.

C. EHR System Design Standards

Whether an EHR system will be deployed from an open source project, purchased from a vendor, or built from scratch, international standards for the system design, as well as locally appropriate configuration options must be taken into consideration. These include:

- **Quality of data being collected:** this is what ultimately determines whether the EHR system will be useful in improving the quality and continuity of care, monitoring treatment outcomes, and providing data for research. The electronic patient record structure and organization should capture and display all information necessary for providing optimal care, such as chemotherapy protocol, blood type and transfusion history, initial malignancy and chronological disease progression.
- **User Interface:** Data should be presented in a culturally appropriate interface that is intuitive and easy to use for finding necessary information quickly.
- **Interoperability:** Recently introduced standards in EHR design focus on the interoperability, which refers to the ability to securely exchange patient data between different EHR systems for the purposes of patient care co-ordination and research data exchange. Compliance with international standards for health care data exchange (such as FHIR by the HL7 system - https://www.hl7.org/fhir/) should be observed when choosing an EHR system.

D. Data quality and record content

Capturing excessively detailed data on a patient chart is not always the best practice, because physicians and health care providers will become inundated and end up spending more time on charting than on providing patient care. The added burden of data capture and entry will lead to inaccuracies and may not end up contributing to an improved standard of care. A balance between feasibility and usefulness of the amount of data needs to be found for each site.

Some considerations include:

- **Diagnosis coding** Where possible, an international system for disease coding should be implemented, such as ICD-10, SNOMED, WHO or COG for specific cancer types. The limitations of this will follow from diagnostic technology limitations in the partner site, when some of the pathological or diagnostic techniques required for making a definite diagnosis or classification may not be available.
- **Geocoding:** records should include the approximate geographic coordinates of where patients currently live. While time consuming, this has many advantages over storing addresses where some LMIC's do not have a conventional street naming or house numbering conventions, or where patients live in remote areas (Wilson et al, 2009). Geocoding helps locate patient residences which can help with case follow-up and reduction of treatment abandonment, as well as assist in identifying areas with high incidence of cancer.

Patient's record

As a bare minimum, a patient's record should contain the following information:

Type of data	Required information
Personal Identification Information and demographics	Name Date of birth (or age if DOB unknown) Sex Medical Record Number Address/Geolocation Ethnicity Parent/caregiver identifying and contact information
Medical History	Allergies Blood group Vaccinations Primary responsible physician Resuscitation status
Family History	Emphasis on occurrence of malignancies, congenital anomalies or unexplained deaths in the family.
Disease history Specific information pertaining to the child's primary malignancy on initial evaluation	Primary diagnosis Initial malignancy classification/staging Onset, course, duration Treatment received Interventions done Comorbidities

Progress and physician notes

Each visit should have progress notes and physician notes including the following data:

Type of data	Required information
Progress Note	Vital signs Anthropometrics: Weight Height BMI Growth charting

Type of data	Required information
Physician notes	Physical assessment Current treatment protocol Previous treatment protocol(s) Latest health events New comorbidities Latest evaluation results for primary malignancy (e.g. Imaging, MRD, blood counts) Latest lab and other investigation results e.g. imaging, blood tests, blood cultures Treatment plan Date and plans for next visit

E. Clinical Decision Support

Integrating clinical decision support systems into an EHR, such as including links to clinical care guidelines, drug references and up-to-date treatment protocols can lead to reducing the variability in clinical practice, improving the overall quality of care, and encouraging self-learning by practitioners in the twinning site. Examples of such resources include the National Cancer Institute Paediatric PDQ (https://www.cancer.gov/publications/pdq/information-summaries/pediatric-treatment), and the MedLine Plus drug information database (https://medlineplus.gov/druginformation.html).

F. Infrastructure

Internet and power outages are commonplace in some LMICS, and therefore the EHR system in the twinning site should be built with redundancies to avoid or minimize disruptions to daily clinical operations:

- **Offline functionality:** Since most contemporary EHR systems are either web applications (operating through a browser window) or rely on an internet/local network connection, care should be taken in selecting and configuring the EHR system to be capable of operating independently on each user's machine in case of a network interruption, saving data locally for synchronization with central server once connection is restored.
- **Power back-up:** In hospital areas where constant access to information is critical, such as the emergency department and intensive care, computers should be equipped with an uninterrupted power supply (UPS) unit to maintain access to basic data and EHR functions in case of a power outage.
- **Backup policy:** A regular backup policy for data stored on the server should be created and rigorously practiced. Both on-site and off-site data backups should be created for maximum data security.

G. Training and Technical Support

Twinning activities will need to include support from the sponsoring organization clinical informatics and IT departments during the initial set up phase and may involve setting up long-term training and maintenance plans at the twinning site. Emphasis must be placed on local capacity building and the formation of a locally sustainable training and technical support model for the EHR system, to ensure long-term, independent sustainability once the twinning program is completed.

Planning and Development of a Cancer Registry

Cancer registries can be hospital-based, pathology-based or population-based, according to the level of complexity of data being collected, number of participating sites and geographical coverage. While hospital- and pathology-based registries serve important administrative and clinical functions, Only population-based registries can provide the necessary level of information needed in formulating cancer prevention and control plans.[36]

Evaluation of local, national and regional cancer registry infrastructure

An important resource for this initial evaluation step is the International Agency for Research on Cancer (IARC), that coordinates the efforts of multiple national and regional registries, and provides a blueprint for planning and developing cancer registries.[36] The 11th edition of the CI5 (cancer incidence in five continents) released by the IARC includes aggregate information from 258 cancer registries around the world, the majority of which are in developing countries.[37] A current list of the participating cancer registries can be found here. Essential questions to answer include:

- Does a local/provincial cancer registry already exist?
- What is the data communication procedure between the twinning site and the local/regional registries, if present?
- Is there a national registry or system of registries?
- What percentage of the population, or percentage of geographic areas in the country, do the existing registries cover?

Quality of data

The IACR has defined standards for measuring the quality and comparability of data being submitted to a cancer registry. Those include the proportion of cases with microscopic verification of cancer (MV%), Mortality to incidence (M-I) Ratio, and percentage of cases reported by death certificate only (DCO%).[36]

For disease coding, IACR requires the use of ICD-O-3 (international classification of diseases for oncology) for data submitted from regional cancer registries, and has made available a free, open-source software package that can be used for input, storage, retrieval and analysis of cancer registry data (CanReg, http://www.iacr.com.fr/canreg5.htm). IACR uses the Toronto Childhood Cancer Stage Guidelines for use as the consensus for staging cancers in paediatric population-based cancer registries, and specifies other criteria for completeness, accuracy and coverage criteria. (http://www.iacr.com.fr/index.php?option=com_content&view=article&id=153&Itemid=657, accessed 10 February 2019)

Partnerships, Governance and Funding

Rather than being independent free-standing organizations, registries in LMICs often operate as part of established institutions that are capable of meeting the requisite quality of data, presence of trained staff, infrastructure and funding to maintain a registry. As such, those registries can be only classified as hospital-based and will seldom provide information representative of the whole population. Partnerships with all healthcare facilities in the area are critical for upgrading hospital-based registries into the population level. Additionally, partnerships help in sustaining cancer registries, both in terms of funding and data submissions.

Cancer registration is a resource and labour-intensive process. Plans for a cancer registry should identify sources of initial funding and implement a sustainability plan. Costs per case registered in LMIC cancer registries ranged from US $3.77 to $15.62, half of which are labour costs. 30-70% of cancer registries in LMICs are funded through contributions from the host institution, with the rest of those resources coming from national, local and international organizations.[31]

Administration and governance of data should ideally be separate and independent, in order to encourage transparency in data sharing and a sustainable operation model. Such partnerships should be codified through memoranda of understanding that govern data sharing and financial responsibilities among all stakeholders.[18]

For those institutions not in a position to implement a full electronic-based registry, we recommend establishing a database that, at a minimum records the following information for each patient whether in a simplified Excel spreadsheet or paper registry where this is the only option:

Type of data	Required information
Demographic Information	Date of first admission Date of first discharge Patient's name(s) Date of birth Patient's hospital ID Gender Ethnicity Phone number Residential address/Geolocation Immunisation status: (Complete for age vs. Incomplete for age) Family history of malignancy
Disease Information	Diagnosis: Presenting symptoms/signs Duration of primary complaint Diagnostic imaging (date, type and results) Pathological diagnosis (date, type and results) Stage of disease at diagnosis
Treatment Information	Treatment Intent (curative or palliative) Treatment protocol administered Surgery (type) Radiotherapy (type and dose) Treatment Response Assessment (per protocol specifications): (good, partial, poor) Treatment outcome (alive with no evidence of disease, alive with active disease, alive on treatment, died of disease, died of other cause, lost to follow up.) Treatment refusal Treatment abandonment

Chapter 8 Behavioural Aspects to promote successful and sustained twinning

Author: Julie Cayrol, MD (Royal Children's Hospital Foundation, Melbourne, Australia)

The experience of different twinning centres across the world has demonstrated that the dedication of each side of the partnership to work together and create good bonds with each other is crucial to the success of a twinning relationship and therefore, of a paediatric oncology program in low resourced settings.

While more research is needed to deeply understand motivations, barriers and enablers to a successful twinning relationship, the following behavioural aspects have been described as being important in the development and sustainability of twinning relationships:

a) Commitment from at least one person in both parties to develop, initiate and maintain the collaborative program. In the LMIC this person is preferably a well-trained paediatric oncologist who can act as a leader in his/her community.[8,21]

b) The relationship should be a respectful and trusting relationship, and not be based on guilt or criticism. It should be a relationship of equals.[8]

c) Financial support for education and training should be available, as it is often difficult to expect staff in low resourced settings to fund their own education. Having funding may increase motivation to attend workshops and seminars. This can be through government support, funding from associations and non-governmental organizations, local foundations, philanthropic funds.

d) Effective and comprehensive communication that can be honest and quick, and based on trust is also very important.[8,22] Both parties must be available to discuss issues, and for this reason, communication is more effective when multimodal (in person, on the phone, via email, etc.), and preferably in a shared language.[38]

Chapter 9 Additional Resources

Adapted treatment regimens

A selection of adapted treatment regimens for centres in low- and middle-income countries are available on through SIOP here:

https://cancerpointe.com/protocols/

Cancer registries

Information about developing cancer registries can be found here:

http://www.rho.org/files/IARC_Planning_developing_cancer_registries_2014.pdf

http://ci5.iarc.fr/CI5I-X/old/vol10/CI5vol10.pdf

Software for Establishing a Cancer Registry can be downloaded here:

http://www.iacr.com.fr/index.php

Twinning Partnerships

The St. Jude Guide to Twinning Partnerships can be downloaded here:

https://cancerpointe.com/download/1986/

A global map of currently active twinning partnerships can be viewed here:

https://cancerpointe.com/twinning-map/

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

https://www.sciencedirect.com/science/article/pii/S2213538313000040

World Child Cancer

For more information about World Child Cancer, an NGO that facilitates twinning partnerships, please visit:

www.worldchildcancer.org

Examples of successful twinning partnerships

Examples of successful twinning partnerships published in the peer-reviewed medical literature include:

Masera GB, F; Biondi, A; et al. North-South twinning in paediatric haemato-oncology: the La Mascota programme, Nicaragua. Lancet 1998;352:1923-6.

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