



Development of paediatric oncology shared-care networks in low-middle income countries



Elizabeth Burns^a, Meg Collington^a, Tim Eden^{a,b,*}, Piera Freccero^a, Lorna Renner^c, Vivian Paintsil^d, Mae Dolendo^e, Afiquel islam^f, Aye Aye Khaing^g, Jon Rosser^a

^a World Child Cancer UK, London, UK

^b Academic Unit of Paediatric and Adolescent Oncology, University of Manchester, UK

^c Korle Bu Teaching Hospital, Accra, Ghana

^d Komfo Anokye Teaching Hospital, Kumasi, Ghana

^e Southern Philippines Medical Centre, Davao, Philippines

^f Bangabandhu Sheikh Mujib Medical University, Dhaka, Bangladesh

^g Yangon Children's Hospital, Yangon, Myanmar

ARTICLE INFO

Keywords:

Optimising childhood cancer care
Shared-care networks-in developing countries

ABSTRACT

In order to reach out and offer optimum access for children with cancer across each country the development of networks of paediatric oncology units rather than just a single centre in one city has been the practice in high income countries over the last 30–40 years and is now being considered by developing countries. At a workshop bringing delegates from 4 countries in Africa and Asia to share their concepts, ideas and experiences of developing such networks and how to move forward, it was recommended that there should be a Hub (referral centre), shared-care centre hospitals, a real emphasis on good communication, ability to train staff within the network and a focus on ensuring that each hospital and country's government must be supportive for it to be successful.

1. Introduction

In 2014 World Child Cancer (WCC) was awarded UK Government (Department for International Development) grants to fund the development of paediatric oncology shared-care centre networks in Ghana and Bangladesh [1]. The objective of the grant was to work towards the achievement of MDGs 1, 4 and 6 in Bangladesh and Ghana by improving diagnosis, treatment and care for over 4700 children with cancer. This was measured by a number of indicators including the number of children diagnosed with cancer across the shared-care networks in Bangladesh and Ghana and the average% increase in survival rates for easily treatable child cancers across the shared-care networks in Bangladesh and Ghana. The 3-year grants enabled improvements both in access to services and the quality of service provision across each country. Improvement in childhood cancer awareness, earlier diagnoses, total care and cancer treatment was achieved across the developing networks. Such a shared-care centre network comprises a number of hospitals working together albeit at often different levels of provision of cancer care for children. The aim is to coordinate care not in just one centre in each country but to enable patients to access at least some of their treatment closer to their homes and in consequence

reduce travel times to hospital, financial burdens on families and rapid access at the time of any acute illness to a team with knowledge of the patient and the treatment required.

The budget for this work included an allowance at the end of the programme for writing up the findings as a resource guide or 'blueprint plan', to share lessons learned and to be made available to others attempting similar work in low and middle-income countries. There is a relative dearth of such literature on network development in low-middle income countries.

1.1. Key definitions

A discussion was generated around the most appropriate key definitions to use in the development of paediatric oncology networks, and minimum criteria agreed for each to function well. The definitions agreed by the group are summarised in Table 1, along with what participants felt are the minimum criteria. This work was done individually by participants, and then the results discussed and agreed upon as a group.

The terms that were under discussion have been used widely within this DfID-funded programme and in other programmes supported by

* Corresponding author at: 5 South Gillsland Road, Edinburgh EH105DE, UK.
E-mail address: tim.eden@edentob.co.uk (T. Eden).

Table 1
Agreed shared-care network definitions.

Term	Definition
Shared-Care Centre	A facility with a relationship to the hub centre that is able to administer maintenance chemotherapy treatment, has a basic level of diagnostics and is able to conduct follow-up of patients. Co-manages patient care and follow-up in conjunction with hub centre.
Shared-Care Network	A network of paediatric cancer wards made up of a hub centre and shared-care centres.
Hub Centre	A tertiary facility coordinating the activities of linked shared-care centres. Equipped with advanced facilities able to treat and diagnose childhood cancer and train multi-disciplinary teams. Supportive care may also be given.
Referral Pathway	Defined process for referral of paediatric cancer patients between two centres.

WCC. It is beneficial to discuss them in order to gain clarity and consensus moving forward, as some are used synonymously across WCC work. The terms discussed were; hub centre, satellite centre, shared-care centre network, shared-care centre, referral centre and referral pathway.

The key findings from the discussion are detailed below.

- Participants agreed that a ‘hub centre’ would always be a ‘referral centre’, and so using the term hub automatically implies that patients will be referred there. Shared-care centres, once at a later stage of development, could also become referral centres so this term could become confusing if used in isolation. The term ‘hub centre’ was therefore agreed to be used, and not ‘referral centre’.
- It was generally agreed that the terms ‘satellite centre’ and ‘shared-care’ centre can be defined as the same type of facility. The group felt that the term ‘shared-care’ is preferred, as this negates any indication of seniority or hierarchy between sites, which could politically cause conflict. It was agreed that WCC would use ‘shared-care’ centre in any future programme work.
- Learning from the information above, the term ‘shared-care network’ is preferred to ‘satellite network’.
- ‘Referral pathway’ was agreed on as the defined process for referral between two centres.

The agreed terms following this exercise were shared-care network, hub centre, shared-care centre and referral pathway.

2. Methods

In order to collect data from various stakeholders to inform this document, WCC organised a 2-day workshop in Dubai. Stakeholders from the two current DfID-funded programmes were invited, along with paediatric oncologists supported by WCC undertaking similar work in other countries where networks were in development. Attendees were included from Ghana, Bangladesh, Myanmar and the Philippines.

The format of the workshop comprised the following areas:

- Challenges, successes and possible “ways forward” summaries from each country
- Discussion around the ‘ideal’ shared-care network model
- Agreement on the most appropriate definitions and terms pertaining to shared-care networks
- Defining minimum criteria for the agreed terms and examining these through the lens of the 6 defined WHO building blocks
- Exploration of key steps towards building a shared-care network
- A reflection on lessons learned and recommendations for planning this type of programme

All participants in the workshop are co-authors of this paper. The lead clinicians from Myanmar and Bangladesh joined the conference on-line and confirmed the outcomes of the discussions.

2.1. Country perspectives

2.1.1. Challenges to developing a shared-care network

It was clear from the discussion that the challenges in developing a service for paediatric oncology in a low-middle income country were similar across the countries represented. Participants stated that increasing patient numbers, with a lack of adequate facilities and/or trained staff were exerting an increasing burden on the existing team. In all cases the oncology services were not fully funded or supported by their governments. The number of new patients can increase faster than shared-care centres can be developed. Logistical issues such as transporting patients between one centre and another, presented a major challenge needing a considerable increase in funding which was difficult to obtain. Communication between hospitals was noted to be a common area of concern with developing teams often lacking the knowledge, technology and time to transfer information. All the delegates stressed that strong communication links are essential for the development of networks. In some countries security issues or civil conflict can hamper attempts to establish networks (Fig. 1).



Fig. 1. The Challenges of developing a shared-care network.



Fig. 2. Successes of Shared-Care Network Development.

2.1.2. Successes achieved in the development of shared-centre networks

The most significant benefit reported was the availability of training opportunities within the networks. As the most essential element for development, it was seen as a key activity to fund. This is helping to build the capacity of sites to provide higher quality care for all patients. Shared-care centres were also felt to be a sustainable solution, comprising home-grown teams of dedicated and empowered staff. The sustainable aspect must come through both local government and hospital administrative support, as well as being shown to have a multiplier effect through the support of local donors and agencies. Regional solutions, bringing people together and sharing lessons learned were also mentioned as strong elements of building a network. As well as the positive developments inside the system, an improvement had been seen in care delivered to patients, numbers of patients diagnosed and the number of children surviving cancer. Enabling children to access healthcare closer to their homes has reduced treatment refusal and subsequent abandonment within developing networks (Fig. 2).

2.1.3. Lessons learned and recommendations on the way forward for others planning such developments

One of the strongest recommendations was to ensure that shared-care centres and staff were selected strategically and carefully to ensure the best chance of success. Collaborative working and good communication are essential elements and should be emphasised at the beginning, as should the support of the hospital administration. The group felt that the best way of working in a network was through sharing and using the same treatment protocols, developing two-way referral systems between centres and sharing successes and any failures. It was also advised that having a strategic and feasible development plan at the outset was crucial. This must comprise a timeline of actions, planned measurable outputs and outcomes, reporting procedures and a budget. The idea of sustainable development was stressed, through step-by-step stages for the project, funding support and “train-the-trainer”

opportunities within the network (Fig. 3).

2.2. The ideal shared-care network

2.2.1. Hub centre

All participants defined a ‘hub’ site at the centre of the network. This is described as a centre of excellence with dedicated space and staff, where training takes place for the multi-disciplinary team involved in paediatric oncology care across the network.

2.2.2. Shared-care centres

The shared-care centre hospitals are linked with the hub centre by a two-way referral and communication process. They will have at least a paediatrician with an interest in oncology and have the ability to perform basic investigations and/or deliver less complicated treatments to patients. Staff from the sites may spend time at the hub receiving specialist training or attending workshops. The sites should be strategically located and accessible to patients in a defined population area away from the Hub Centre. As they develop they may establish their own mini shared-care centres to further improve accessibility, lighten the patient load at their centre and deliver some care closer to patients’ homes.

Under-pinning these depictions were strong themes of resourcing and support, through funding from NGO’s or Governments, and support from Health Service administration and policy makers.

2.3. WHO building blocks for health system strengthening

The World Health Organisation describes health systems in terms of 6 core components or “building blocks”. These are (i) service delivery (ii) health workforce (iii) health information systems (iv) access to essential medicines (v) financing (vi) leadership and governance.

Participants were earlier asked to consider the criteria necessary for



Fig. 3. Lessons learned from shared-care network development.

a WHO building blocks: service delivery, health workforce, information systems

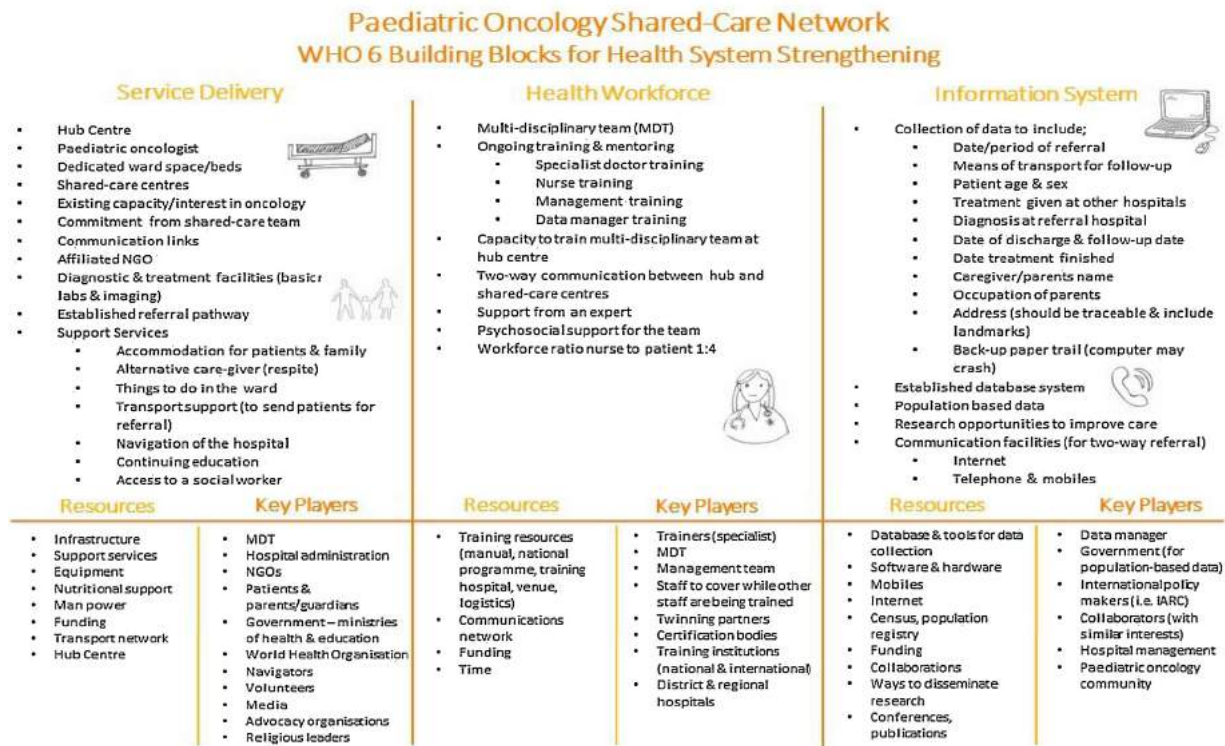


Fig. 4. (a) WHO building blocks: service delivery, health workforce, information systems. (b) WHO building blocks: access to essential medicines, financing, leadership & governance.

a shared-care network to function well (*key definitions*). Building on this work to list the minimum criteria for a functioning network, the participants rearranged the listed criteria under the most appropriate WHO building block. They were then each given a different stakeholder scenario and asked to re-do the criteria exercise with a ‘different hat on’. This enabled us to build up a picture of the key elements which are required for a functioning shared-care network, organised under the WHO framework. Participants also worked together to define the resources needed and the key actors under each block, considering the criteria defined.

A summary of the building blocks exercise is included in Fig. 4a and b, along with resources and key actors identified.

The stakeholder scenarios used for the exercise were; doctor at a shared-care hospital, patient or parent, nurse at hub hospital and a data manager at a hub hospital.

2.4. Key steps to building a shared-care network

Fig. 5 visually depicts the combined thoughts of the group on the key steps necessary for developing shared-care networks in LMIC. This work was done in two groups which each had either an African or an Asian regional focus. A comparison at the end of the exercise showed that each group had described similar steps. The diagram contains some elements described by individuals as if there were no constraints on resources and consequently may take time to implement.

The combined steps are more appropriately shown as diagrams, as they are not linear in nature. The elements agreed on are summarised below.

- Hub centre: requires a committed doctor with interest/training in paediatric oncology, dedicated bed space, a multi-disciplinary team, training must be available, patient data accurately recorded, drugs available and research opportunities accessible. A health partnership with an external developed centre is beneficial. A tangible plan,

measurable outcomes and financial support are needed for development into a centre of excellence. Support would ideally be available for patients and families, to include accommodation, treatment costs, food and transport.

- Strong communication networks must link the hub with any shared-care centres developed, to maintain sustainable relationships and develop two-way referral pathways.
- Shared-care centres: need to have an interested doctor, access to some basic training, some ward space for oncology patients, the support of the hospital administration and a basic multi-disciplinary team. Patient data needs to be stored, at least on paper, and there must be a relationship with a hub centre.
- The over-arching principle of sustainability needs to be emphasised through the availability of training within the system (preferably an in-country fellowship programme) and funding. Sharing, learning and replicating within the system are important elements.

2.5. Reflection

At the close of the workshop, participants were asked some reflection questions to draw out any conclusions or pertinent observations which had not been captured already, or that the group wished to emphasise. The questions and findings are summarised below.

Would you do anything differently if starting this work again?

- There should be an MOU between hub and shared-care centres, to strengthen the understanding of the teams and of hospital management. It should define responsibilities and timeframes. It is also much easier to achieve conformity and guidelines if hospital management are involved from the start of the programme.
- There should be oversight from the hub on the activities at shared-care centres, especially regarding treatment protocols.
- Communication links need to be stronger, and visits to the shared-care centres in person are important.

b WHO building blocks: access to essential medicines, financing, leadership & governance

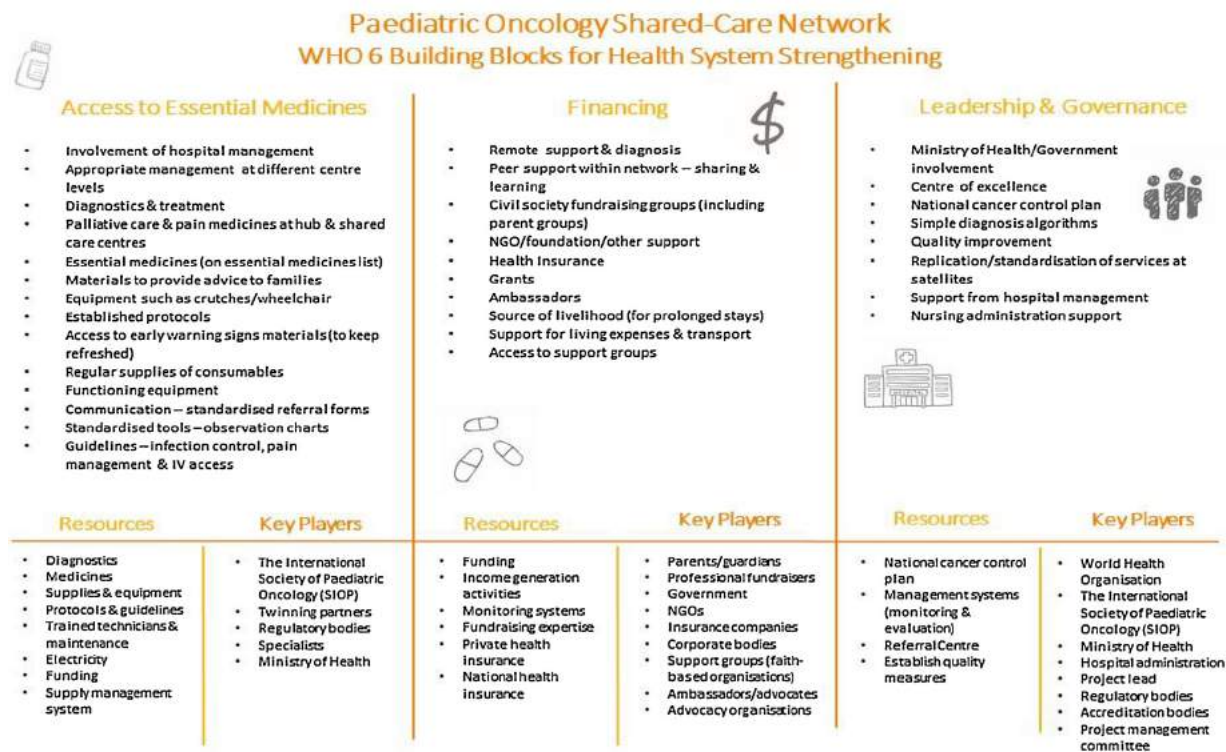


Fig. 4. (continued)

- A Project Committee or Steering Group is important for decision-making processes and should comprise a range of stakeholders. This avoids the situation of all decisions being left with the defined project lead.
- Outcome measures should be developed for each of the health system building blocks. These should include quality of life measures, where in the short-term the biggest impact will be seen.

Would you revise the way forward as previously presented to the group?

- Prioritisation on talking and collaborating more within the network.
- Development of a network using the structures and systems of the WHO building blocks framework.
- Would put emphasis on revising treatment guidelines; simplifying these and putting them in a public space for staff to see them clearly.
- Implement more regular refresher training for staff at shared-care centres to build confidence, and while there needs to be a focus on early warning signs & symptoms topics such as palliative care should also be included.
- Mentoring for centres could be better to dispel feelings of isolation.

Are you taking away any new ideas from this workshop?

- Encouraging simple research in audit form to enable quality improvements.
- WHO building blocks are a useful planning tool and will help with programme management and strategies.
- Sharing with the centres in the network how they can become sustainable and emphasise local support rather than waiting for support to come from above.
- Having ‘celebration of life’ parties to raise awareness and provide psychological support.

What is the role of World Child Cancer in this work?

- A platform for exchanging information and for funding.
- Organising training and workshops, which are essential for empowering healthcare staff.
- ‘Movers and shakers’ of the network development as would not have previously thought of linking up with the other centres.
- Helped put childhood cancer on the political map/scene through advocacy and meetings with policy makers, and kept hospital management thinking about childhood cancer.
- Ongoing capacity building, data strengthening.
- Development of fundraising skills for parent groups.
- Have not been intrusive, have included stakeholders right from outset and the needs assessment, been supportive, allow in-country stakeholders to work on programmes themselves and present WCC with budget for their needs.
- Created an enabling environment for childhood cancer management to improve.
- Enriched the experience of child with cancer and the journey of the family.
- Give the opportunity to share and learn with other projects so they don’t go through the same mistakes and can shorten journey to improved care for paediatric cancer.

How could WCC help in the future?

- Make more of an impact with capacity building – one week workshop rather than a 2-day course.
- Strengthen twinning partners. Partners should be proud of the partnership, boast about the achievements and be able to give time. Some of the twinning partners have not involved hospital management as much as they should have, the involvement is more at clinician level. If management had signed the MOU they may have had more ownership.
- Regional training workshops (with other countries like Malawi, Cameroon) would be helpful to build capacity. The workshop should last for 1 week and focus on just one topic like Leukaemia,

Key Steps to Building a Paediatric Oncology Shared-Care Network

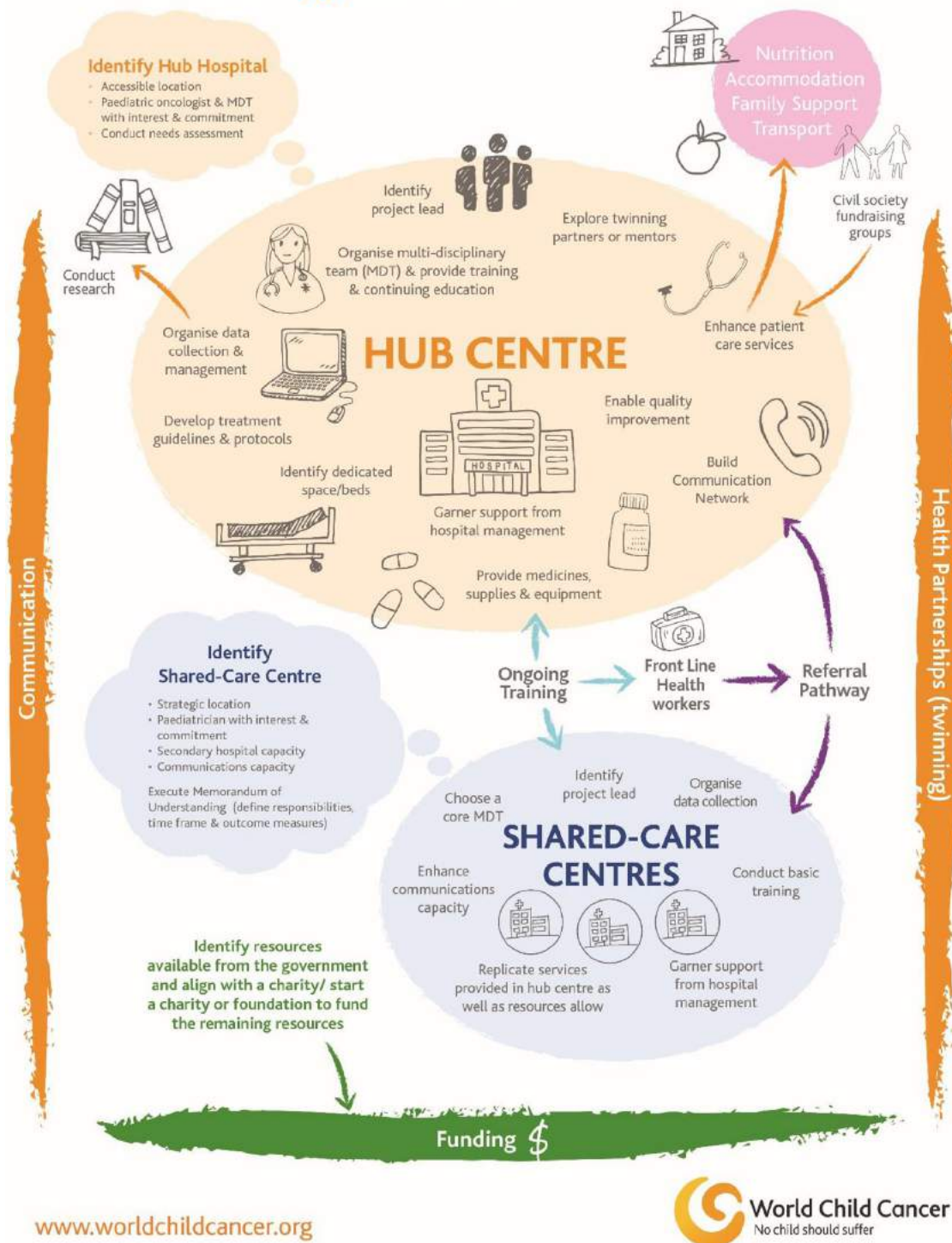


Fig. 5. Key Steps to Building a Paediatric Oncology Shared-Care Network.

Retinoblastoma or Oncology Nursing. It would deal with the issue from basics, genetics, treatment, rehabilitation.

- Shared-care centre get-together learning workshops – have not brought all the centres together before.

3. Discussion

There is such a disparity in survival for children with cancer in low-income countries compared with those in high-income countries [2–5] that as paediatricians start to see an increase in children presenting

with cancer at their hospitals they frequently seek help from those in established paediatric cancer centres elsewhere. Development of international health partnerships has been a good way to provide advice; share expertise gained from experiences of successes and failures over the last few decades in high income countries; provide support for training, and enable technology transfer to help those starting up cancer care services to overcome the challenges facing them [6–10]. It is essential that the ownership of any development is in the hands of those in each country trying to develop a cancer service and not by the supporting high-income partner. Usually with hospital to hospital partnerships, the initial project is always to create an effective single hub centre with adequate space, staffing, equipment, access to medicines and a training programme. However, if all children in a country who develop a malignancy are to be diagnosed and treated in an appropriate and timely way a single unit, most often in the country's capital, will not be able to reach out to all children who need help. Creation of shared-care networks is how high-income countries have developed their services over the last few decades with significant success and is a concept well worth sharing. What each shared-centre can provide for patients depends on adequate staffing, training and capacity. Some hospitals can provide basic investigations, blood tests, and sanctuary of first call when a child is ill at home whilst others are able to provide some or, in due course as they develop, all of treatment after initial diagnostics at a hub centre. All of this has led to development of “hub and spoke” networks with an essential need for good communication and a collective team approach. There is a relative dearth of papers describing the optimal way to create such a network within low-middle income countries [7–9,11].

Clearly the major challenges are to obtain hospital administration support and even more importantly, governmental support and financing for such developments. Without universal health coverage, the cost of treating a child with cancer falls on the families [12,13] but service delivery must be the duty of health providers and governments. Ribeiro et al. reported that 5-year survival for children in 10 low to middle-income countries was directly proportional to per capita annual total health expenditure, per capita gross domestic product, per capita gross national income, number of physicians and nurses per 1000 population and annual governmental health-care expenditure per capita [14]. As countries improve economically then it is essential that the case is made to health care providers and governments that they do need to develop paediatric services including for childhood malignancies. Childhood cancer has increased significantly worldwide since the 1980s especially following progressive reduction of communicable diseases in the last 15–20 years [15,16] and it is predicted to become more prevalent in LMICs just as it did in high income ones from the 1960s onwards.

The workshop was a successful way of bringing together stakeholders involved with the shared-care centre development programmes and other colleagues who had already created a network to share their experiences in developing such a network. It was a useful mechanism to develop coherent steps to potentially help others in the future trying to undertake this type of work, and for informing the next stages of World Child Cancer programmes.

A resource manual will be developed using the information and diagrams in this report, to be made available to the paediatric oncology community for those wishing to develop shared-care programmes.

Conflict of interest

None of the authors have any conflict of interest.

Acknowledgements

We would like to thank our partners from Ghana, Bangladesh, the Philippines and Myanmar for participating in this work.

References

- [1] E. Burns, T. Eden, J. Rosser, World child cancer: supporting partnership models in paediatric oncology, *Cancer Control* (2016) 22–26.
- [2] L.M. McGregor, M.L. Metzger, R. Sanders, V.M. Santana, Paediatric cancer in the new millennium: dramatic progress, new challenges, *Oncology* 21 (7) (2007) 809–820.
- [3] K. Pritchard-Jones, R. Pieters, G.H. Reaman, L. Hjorth, P. Downie, G. Calaminus, et al., Sustaining innovation and improvement in the treatment of childhood cancer: lessons from high income countries, *Lancet Oncol.* 14 (3) (2013) e95–e103, [http://dx.doi.org/10.1016/s1470-2045\(13\)70010-x](http://dx.doi.org/10.1016/s1470-2045(13)70010-x).
- [4] I. Magrath, E. Steliarova-Foucher, S. Epelman, R.C. Ribeiro, M. Harif, C.-K. Li, et al., Pediatric cancer in low-income and middle-income countries, *Lancet Oncol.* 14 (3) (2013) e104–116, [http://dx.doi.org/10.1016/S1470-2045\(13\)70008-1](http://dx.doi.org/10.1016/S1470-2045(13)70008-1).
- [5] K. Pritchard-Jones, R. Sullivan, Children with cancer: driving the global agenda, *Lancet Oncol.* 14 (March) (2013) 189–191.
- [6] J. Hopkins, E. Burns, T. Eden, International twinning partnerships: an effective method of improving diagnosis, treatment and care for children with cancer in low-middle income countries, *J. Cancer Policy* (1–2) (2013) e8–e19, <http://dx.doi.org/10.1016/j.jcpo.2013.06.001>.
- [7] R.C. Ribeiro, C.-H. Pui, Saving the children: improving childhood cancer treatment in developing countries, *New Engl. J. Med.* 352 (2005) 2158–2160.
- [8] S.C. Howard, M. Pedrosa, M. Lins, A. Pedrosa, C.-H. Pui, R.C. Ribeiro, et al., Establishment of a paediatric oncology program and outcomes of childhood lymphoblastic leukaemia in a resource-poor area, *J. Am. Med. Assoc.* 291 (2004) 2471–2475.
- [9] G. Masera, F. Baez, A. Biondi, F. Cavilli, V. Conter, A. Flores, et al., North-South twinning in paediatric haematology-oncology: the La Mascota Programme: Nicaragua, *Lancet* 352 (1998) 1923–1926.
- [10] L.A. Renner, C. Segbefia, E. Johnson, E. Burns, V. Sharma, S. Kerr, et al., Challenges and success in a twinning partnership in Ghana, *Oncol. News* 8 (2) (2013) 20–22.
- [11] S. Gupta, R. Rivera-Luna, R.C. Ribeiro, S.C. Howard, Paediatric Oncology as the next Global Health priority: the need for National Childhood Cancer Strategies in low-middle income countries, *PLoS Med.* 11 (6) (2014) e1001656.
- [12] A. Islam, A. Akhter, T. Eden, Cost of treatment for children with acute lymphoblastic leukemia in Bangladesh, *J. Cancer Policy* 6 (2015) 37–43.
- [13] S. Mostert, C.M. Sitaresmi, S. Gundy, S. Sutaryo, A.J.P. Veerman, Influence of socioeconomic status on childhood acute lymphoblastic leukemia treatment in Indonesia, *Pediatrics* (2006) e1600–e1606.
- [14] R.C. Ribeiro, E. Steliarova-Foucher, I. Magrath, J. Lemerle, T. Eden, C. Forget, et al., Baseline status of paediatric oncology care in ten low- income and mid-income countries receiving My Child Matters support: a descriptive study, *Lancet Oncol.* 9 (2008) 721–729.
- [15] L. Liu, H.L. Johnson, S. Cousens, J. Perin, S. Scott, J.E. Lawn, et al., Global, regional and national causes of child mortality: an updated systematic analysis for 2010 with time trends since 2000, *Lancet* 379 (2012) 2151–2161.
- [16] E. Steliarova-Foucher, M. Colombet, L.A.G. Ries, F. Moreno, A. Dolya, F. Bray, et al., International incidence of childhood cancer 2001–10: a population-based registry study, *Lancet Oncol.* (April) (2017), [http://dx.doi.org/10.1016/S1470-2045\(17\)30186-9](http://dx.doi.org/10.1016/S1470-2045(17)30186-9).