Challenges for Cancer Care in the Pacific and how to move forward:

The Pacific Child Cancer project

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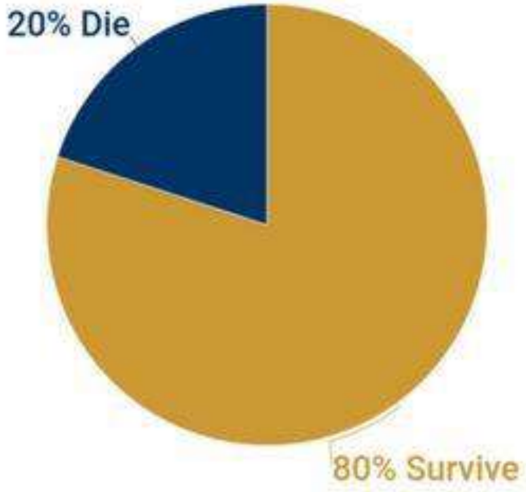
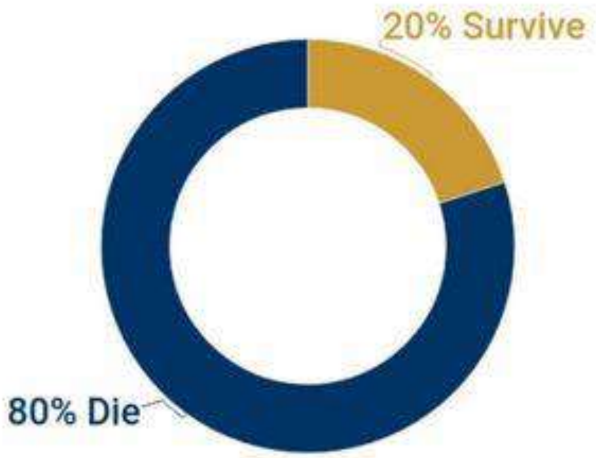
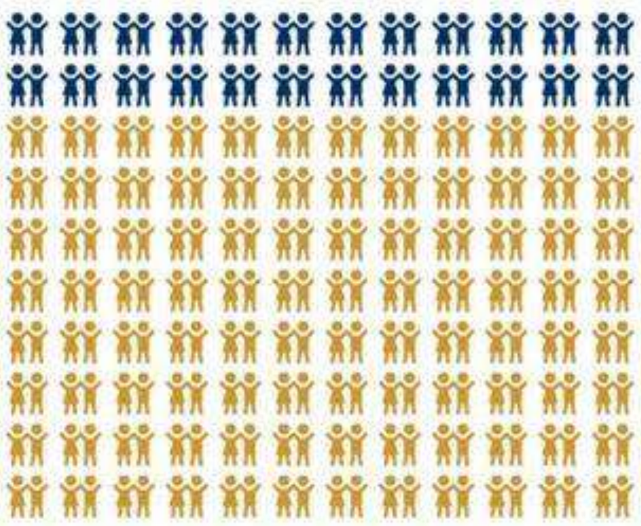
Childhood Cancer 5 Year Survival in Developed Countries



Childhood Cancer 5 Year Survival in Low-Middle-Income Countries





80% of all children with cancer live in low-middle-income countries

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KYOTO, JAPAN | NOVEMBER 16-19, 2018

Outline

- Global burden of child cancer
- Background NCCN Pacific Working group
- NZ Aid funding 2006-2008
- NZCCR 2005-2014: incidence and survival data by prioritised ethnicity
- Pacific country specific models of care
- Parent support by NGO’s and Early warning signs childhood cancer
- Gains, challenges and the future
- Global stage

- Childhood cancer is a major global health issue
- Every year, almost 200,000 children are diagnosed with cancer and almost 100,000 die from cancer before the age of 15 years, more than 80% of them in resource-limited countries.
- **Cancer in children and adolescents is rare and biologically very different from cancer in adults**
- It accounts for 1·4% of all cancers worldwide
- Worldwide a child is diagnosed with cancer every 2 minutes

As the health of children in the Pacific improves
childhood cancer is emerging
as a significant cause of morbidity
and premature death

Background

2005 NZ Paediatric Oncologists raised concerns about child cancer in the pacific:

Few cases referred to New Zealand for treatment - often wrong cases, usually way too late

- How were these selected?
- What happened to the rest?
- Huge cost if treated in New Zealand and no return of expertise to the referring country
- There had to be a better way

Pacific working group was set up in 2006 under the governance of the Paediatric Oncology Steering Group (POSG)

1. To review outcomes of children referred from the Pacific
2. To investigate whether twinning with Pacific nations was feasible
3. To initiate cooperative programmes with those nations which regarded child cancer as a priority health area

Note: in 2011 POSG became National Child Cancer Network (NCCN)

PAEDIATRIC
ONCOLOGY
STEERING GROUP

NationalChild
CancerNetwork NZ
Linking Care / Sharing Knowledge / Advancing Best Practice

Audit (1990-2007) Starship, Auckland

- 51 cases referred from Pacific for treatment with largely unsatisfactory outcomes
- If returned to respective Pacific Island whilst still on treatment- with no training in country-majority died from an intercurrent infection (gastrointestinal/respiratory)
- Discrepancy in survival of referred cases not related to ethnicity
- Survival of NZ resident Pacific children treated in NZ same as for non-Pacific

What happens when HIC protocols used in LMIC ?

- Total XI protocol for childhood ALL 72 % EFS (USA), but when implemented in Recife, Brazil EFS 32%

Howard SC et al. *JAMA 2004;291:2471-2475*

When protocol adapted (anthracycline removed) in El Salvador

- EFS went from <10 to 48%
- but toxic death rate 48% in induction and another 4.6% in remission
- therefore need to identify where to make improvements, such as supportive cares

Bonilla M et al. *J Pediatr Hematol Oncol. 2000;22:495-501*

TOR: NCCN Pacific Working group (2011)

Purpose

- to develop, implement and monitor service delivery solutions that improve outcomes for children with cancer in Pacific Island Countries and thereby manage the impact of this patient group on health care services delivered in New Zealand.

Objectives

- Facilitate building of capacity and resources in the Pacific Islands.
- Improve access to in-country treatment for children and young people with cancer in the Pacific Islands
- Improve outcomes for children with cancer in Pacific Island Countries
  Enable effective planning for child cancer patients from the Pacific arriving in New Zealand for treatment

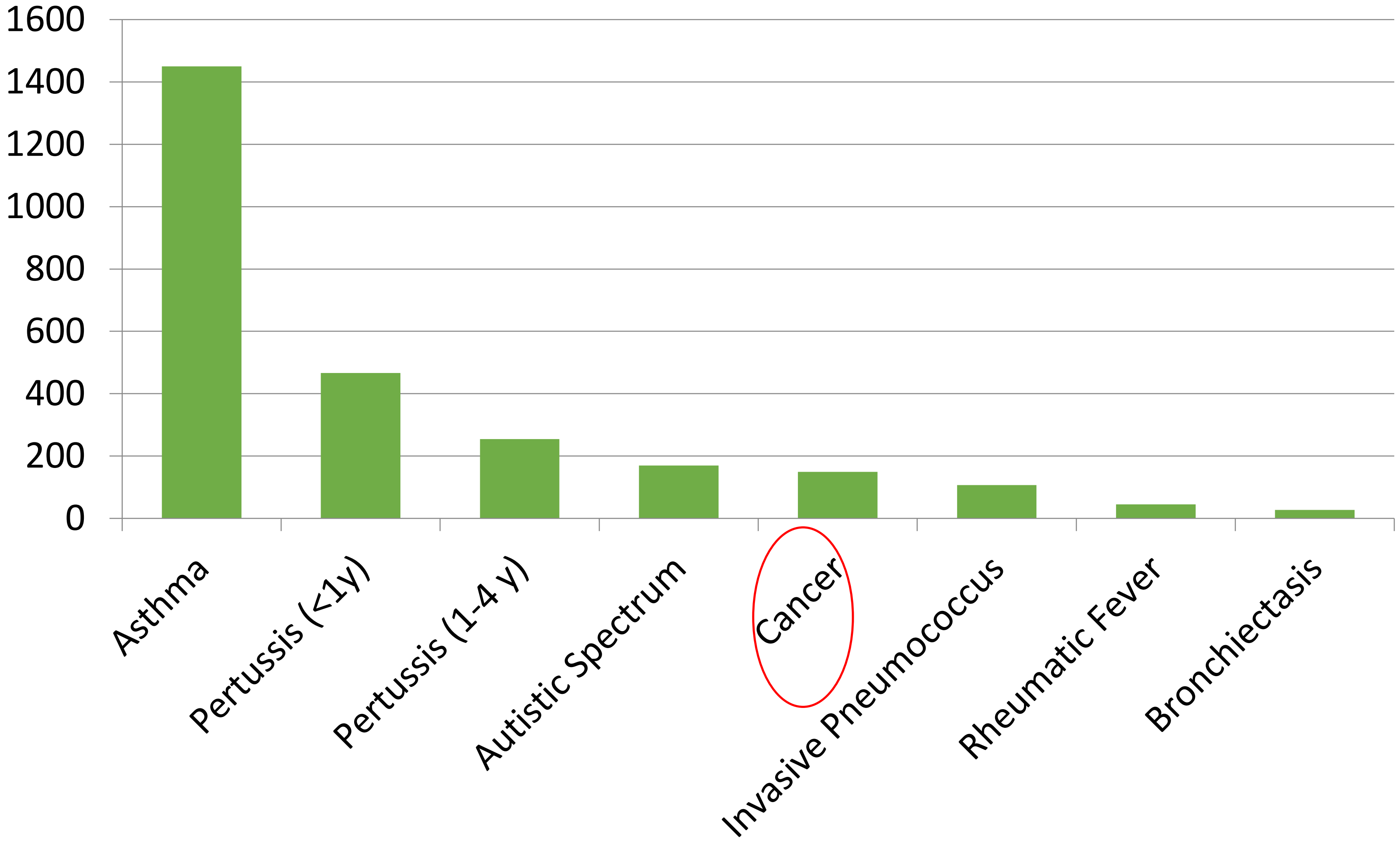
The current situation in NZ

- 150 children (<15yrs) are diagnosed with cancer each year
- ~80% of them will be cured as a result of contemporary therapy
- About half will live completely normal lives, the others will have residual issues related to treatment or their original cancer

- **Incidence of Child Cancer (NZCCR 2000-2009)**

  149.3 per 10,000 children per year **(age 0-14.9)**

Age adjusted incidence per 10,000 children per year



IMPROVING THE ACCURACY AND COMPLETENESS OF NEW ZEALAND CHILD CANCER REGISTRATION: THE BENEFIT OF TWO NATIONAL REGISTRIES

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[1] Children's Haematology / Oncology Centre, Christchurch [2] National Child Cancer Network, Auckland [3] Starship Blood and Cancer Centre, Auckland
[4] New Zealand Cancer Registry, Ministry of Health, Wellington

Background / Objectives

New Zealand has two cancer registries covering childhood cancers; the New Zealand Children's Cancer Registry (NZCCR), based in the two specialist paediatric oncology centres, and the New Zealand Cancer Registry (NZCR), a population-based register of primary malignant tumours. Both registries collaborated to determine the accuracy and completeness of child cancer registration.

Materials and Methods

2010-2014 registrations for children aged under 15 years that met International Classification of Childhood Cancers (ICCC-3) criteria were obtained from each registry and matched by National Health Index (NHI) number. Anomalies were reconciled using patient management systems, clinical summaries and laboratory reports.

Results - Accuracy

Following review, 2 records were removed from the NZCCR and 19 from the NZCR – primarily due to the registration of children who came from the Pacific Islands for treatment. In addition, errors were corrected for sex (n=5), age at diagnosis (n=15), and ICD-O site/histology resulting in a change of ICCC-3 diagnostic group/subgroup (n=25).

Registered in error	NZCR	NZCCR	Any
Total notifications	**716**	**721**	**794**
Incorrect date of diagnosis (pre 2010)	-	1	1
Non-malignant tumour	6	1	7
Relapse registered as a new primary	1	-	1
Overseas at diagnosis	19	-	19
Inclusion criteria differences	4	-	4
Total notifications removed	**30**	**2**	**32**
Total notifications confirmed	**686**	**719**	**762**

Results - Completeness

Of the 794 unique cases identified, 643 cases were informed by both registries. By ICCC-3 subgroup, NZCCR particularly under-reported 'XId: melanomas' and 'Id: myelodysplastic syndrome' while NZCR under-reported 'IId miscellaneous lymphoreticular neoplasms' and 'IIIb: astrocytomas'. Case completeness (according to their respective registration criteria) was 99% for the NZCR and 94% for the NZCCR.

Cases informed by one registry only	NZCR	NZCCR	TOTAL
Non-malignant CNS tumours[1]		55	55
LCH prior to 1/1/2014[2]		16	16
Missed by second registry in error	18	5	23
Diagnosed <1 week prior to death	5		5
Case not referred to a specialist centre	18		18
Pending registration as at 1/1/2016	2		2
TOTAL	**43**	**76**	**119**

[1] NZCR does not register non-malignant tumours, NZCCR registers ***all*** CNS tumours as per ICCC-3

[2] NZCR registered LCH from 2014 (the date the ICD-O-3-1 was implemented), NZCCR from 2010

Total cases by ICCC-3		NZCR	NZCCR	FINAL
I	Leukaemias	265	249	254
II	Lymphomas	69	79	82
III	CNS tumours	109	150	158
IV	Neuroblastoma	59	55	56
V	Retinoblastoma	30	27	28
VI	Renal tumours	35	33	33
VII	Hepatic tumours	14	12	14
VIII	Bone sarcomas	48	42	45
IX	Soft tissue sarcomas	41	43	44
X	Germ cell tumours	19	17	22
XI	Carcinomas	25	14	25
XII	Other	2	0	1

Discussion

Collaboration resulted in the reporting of an average of 152 annual child cancer cases meeting ICCC-3 criteria each year compared to the 143-144 identified by either registry alone. Age-standardised child cancer incidence for 2010-2014 was 167 per million (95%CI: 155-179).

Analysis of the accuracy and completeness of child cancer registrations highlighted each registry's respective strengths;

NZCCR

- ✓ Registers non-malignant CNS tumours
- ✓ Identifies overseas patients coming to NZ for treatment & excludes from incidence counts
- ✓ Is updated if a diagnosis changes following expert review
- ✓ Can make registry modifications readily (e.g. ICD-O revisions)
- ✓ Includes comprehensive diagnostic and treatment information for patient care, service planning, and research

NZCR

- ✓ Mandatory pathological reporting – includes cases not referred to specialist centres
- ✓ Includes cases diagnosed at autopsy / death certificate only
- ✓ Cancers are registered by expert clinical coders
- ✓ Access to date of death directly from the NHI
- ✓ Many fields are automatically populated from the NHI, reducing data entry errors

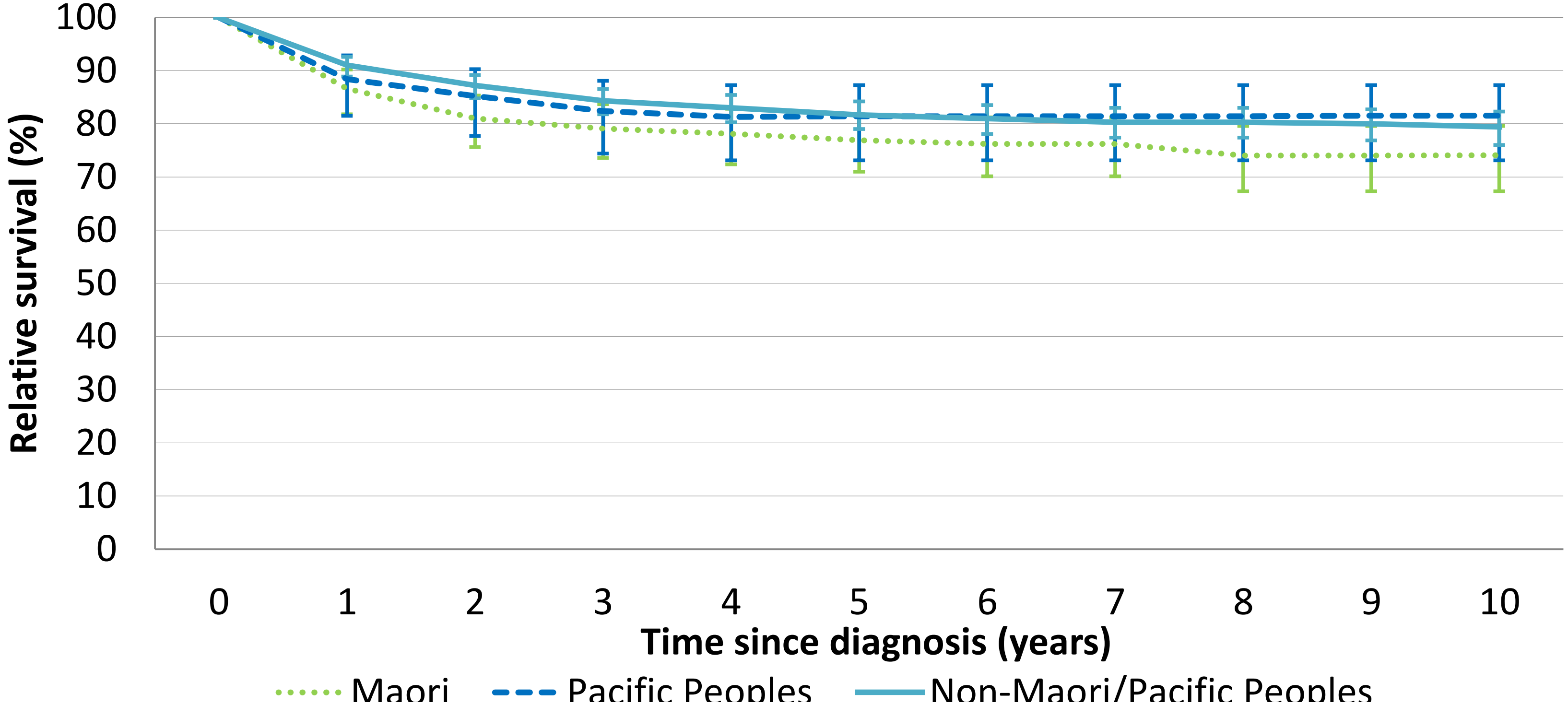
Conclusion

This study has identified improvements that can be made in the registration processes of each registry and some gaps in New Zealand's child cancer referral pathways which require addressing at a national level. With two registries covering childhood cancers, New Zealand is uniquely positioned to undertake regular collaborative activities, thereby ensuring that highly accurate and complete data is available for research and statistical reporting purposes.

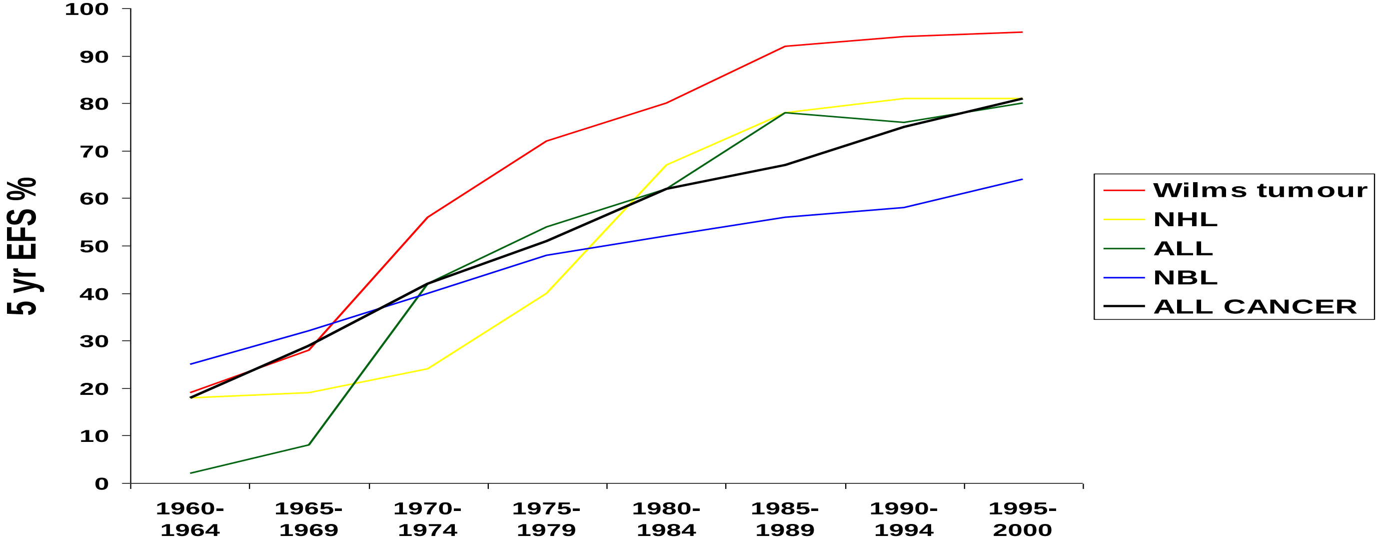
NZCCR 2005-2014

- Cancer incidence in New Zealand is comparable to elsewhere in the developed world
- There are no significant differences in incidence between Maori, Pacific Peoples and Non-Maori/Non-Pacific Peoples
- Relative Survival (83.6% at 5yrs) in New Zealand is comparable with elsewhere in the developed world
- In New Zealand relative survival for Maori and Pacific Peoples is comparable to Non-Maori/Non-Pacific Peoples

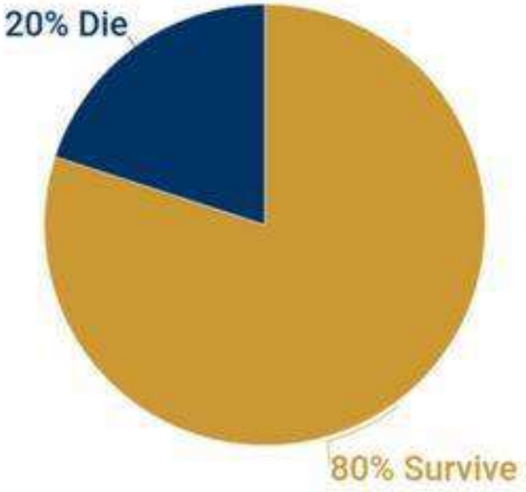
Survival by Prioritised Ethnicity



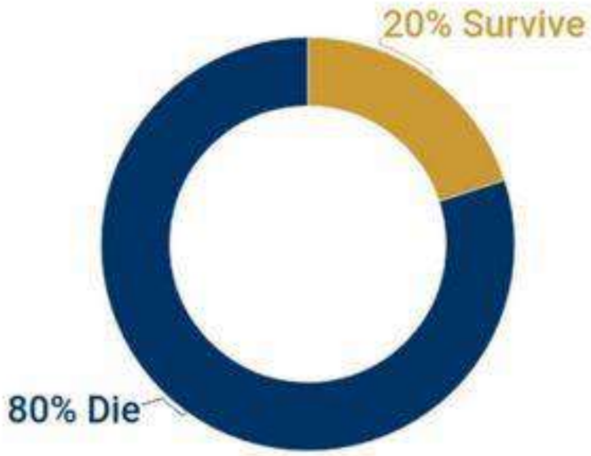
Survival for children with cancer in developed countries

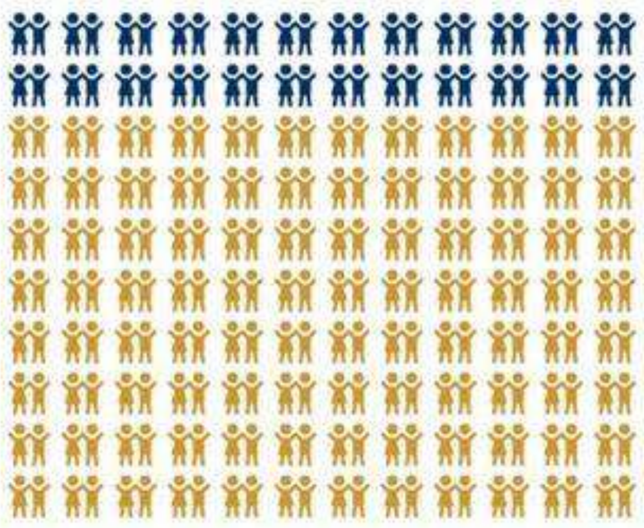


Childhood Cancer 5 Year Survival in Developed Countries



Childhood Cancer 5 Year Survival in Low-Middle-Income Countries





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GAP- between HIC and LMIC

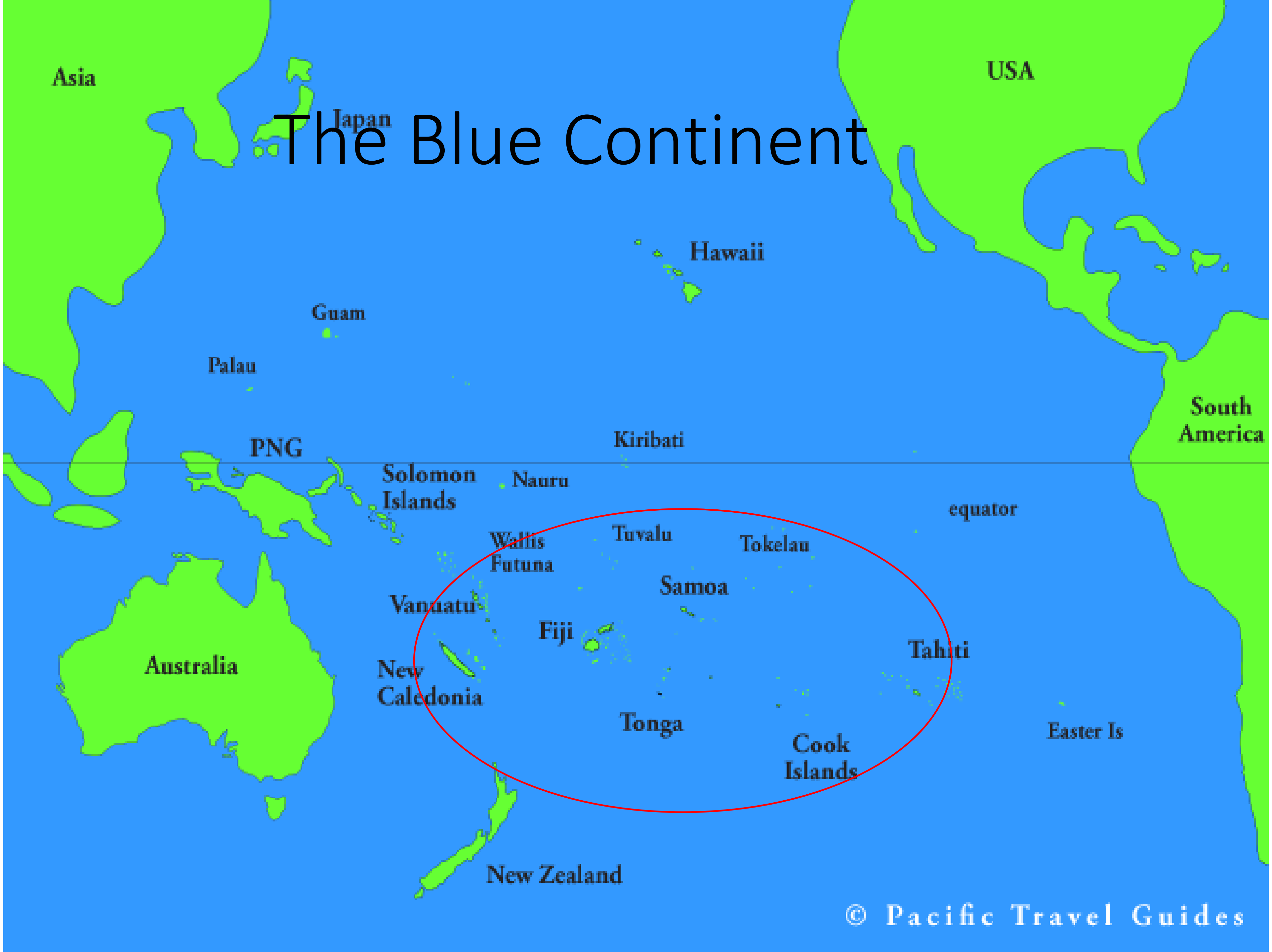
- Children with cancer are not all created equal
- Where they live does make a difference to whether they are offered treatment, survive or die
- More than **80%** of the children worldwide live in less affluent countries
  (LMIC-including the Pacific)
  where childhood malignancies form an important part of the morbidity and access to adequate treatment is often not possible – with overall survival **< 20%**

- **80%** resources worldwide consumed by the **20%** treated with modern therapy where overall survival **80%**
- Cure rates of around **50%** for many types of childhood cancer are possible in less well resourced countries with lower cost therapies, providing basic services can be organised and supported

Pacific working group

- 2006-2008: Secured 2 years funding from NZAid
- Advise and mentorship by Pacific health professionals in NZ (Dr Kiki Maoate, Dr Api Talemaitoga and Debbie Sorensen)
- Visits- to countries aligned to NZ Aid
  -Fiji, Tonga, Samoa, Cook Islands, Vanuatu
- Met with MOH, NZ High Commissioner and Health professionals in country

The Blue Continent



Childhood Cancer in the Pacific

- Assume incidence same as NZ @140/million child years
- 40% population<15yrs
- (NZ: 24% <15 yrs)

- French Polynesia has published a rate of 125/million between 1985 and 1995

- Need for a Pacific Child Cancer registry

PNG	420
Fiji	**47.5**
Solomons	26.8
Vanuatu	**11.8**
Samoa	**10.4**
Tonga	**5.7**
Kiribati	5.5
Cook Islands	**1.8**
Tuvalu	0.56
Tokelau	**0.06**
Niue	**0.06**

Various myths persist about cancer in the Pacific

- Cancer is incurable
- Cancer is shameful and best not diagnosed
- When it occurs in Pacific peoples, the outlook is much worse than for other ethnic groups
- Cancer treatment is prohibitively expensive
- Cancer treatment is too complex for Pacific health systems

In collaboration with Pacific Health Professionals

agreement on:

- Philosophy behind treatment protocols
- Our Pacific colleagues *“limited resource let’s direct it to where will get best gains”*
- **Country specific models**

Twinning relationships

- Christchurch with Fiji
- Starship with Tonga, Samoa, Vanuatu, Cooks, Tokelau, Niue

establishment of:

- Triage criteria
- Treatment protocols
- Supportive Care Guidelines
- Cancer registration form

- Regional meetings
- Nursing education/training in Auckland and Christchurch for nurses from Fiji and Tonga
- Laptops/digital camera for Samoa/Tonga and Fiji

Country specific models

- The Pacific is a region with a small, widely dispersed population which makes models successfully used elsewhere (Africa, South America) inappropriate
- Different needs within the region
- Different capabilities and priorities
- Different solutions
- Different speed of implementation

- Is curative therapy for children with cancer a priority?
- Is the paediatric infrastructure developed?
- Is finance available for off island referral?
- Are there sufficient patient numbers to develop expertise at the paediatric centre?

Fiji

- Cancer treatment a priority
- 2 Paediatric centres (Lautoka, Suva + ?Labassa)
- Limited finance for off-island referral but
- Public health care available for treatment in Fiji
- 40-50 new child cancer cases expected each year

Solution:

- Treat on PI protocols at the 2 centres with remote support / twinning from Christchurch, NZ
- Visits by Christchurch team to Fiji
- Regular video/tele- conferencing with Suva / Lautoka and Christchurch

Tonga

- Child cancer treatment a priority
- Paediatric service, Vaiola Hospital, Nuku’alofa
- Limited finance for off-island treatment
- Small numbers (<10 new cancer patients/year) so not enough for a cancer centre but enough to share care with an external oncology centre

Solution:

- Diagnose
- Triage as per guidelines
- ALL-start PI ALL#1 and if favourable response Day 8 send eligible patients to Starship Auckland for induction/consolidation then repatriate to complete protocol in Tonga with remote support from Starship
- Other cancers as per guideline

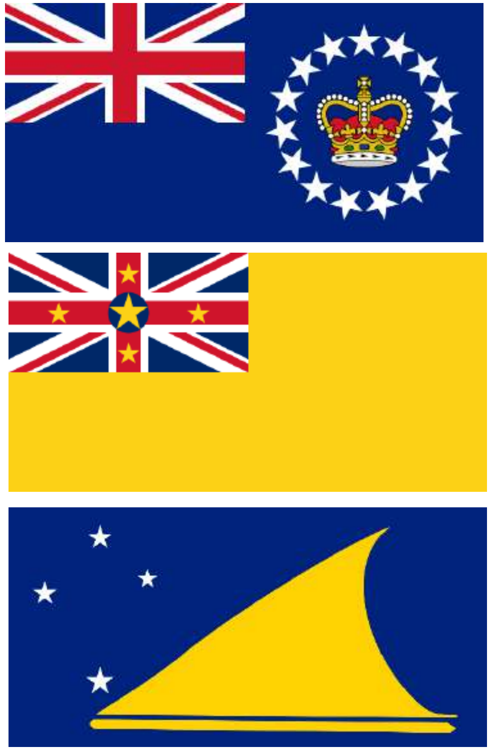
Samoa

- Child Cancer treatment being considered as a priority in 2007 – confirmed 2010
- Paediatric service at TTM hospital, Apia
- Limited finance for off island treatment
- Small numbers (<10 new cancer patients/year) so not enough for a child cancer centre but enough to share care with an external oncology centre (Starship, Auckland)

Solution:

- Diagnose, triage as per guidelines
- Model as for Tonga

Cook Is / Niue / Tokelau



- Child Cancer treatment a priority (and expectation)
- Paediatrics only in Rarotonga (Cook Islands)
- Very few patients
  1 / 1-2 years
- Finance available (entitlement to care in NZ)

Solution:

- Transport to NZ for treatment on COG and other established protocols

Vanuatu   (as of 2007)

- Child Cancer treatment not a priority
- Limited paediatric expertise
- Limited finance for off island treatment

Solution:

- Provide information including palliative care guidelines
- Remain available for advice and discussion
- When becomes a priority- model as for Tonga and Samoa

In summary

- Co-operative program development is vital
- Establish relationships with key clinical and political decision makers
- Confirm that child cancer care is a priority
- Identify champions with local status
- Commit to the long term
- Identify the needs
- Understand that needs are different and solutions which work somewhere else may be inappropriate
- Assemble resources relevant to the area and develop protocols and guidelines cooperatively with those who will need to use them

Alignment with country's Health Plan and Sustainable Development Goals

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Principles of triage

- an initial “cut-off” level of around 70% overall survival *in developed countries* is reasonable
- it is assumed that the 70% overall survival will translate into a lower survival in the Pacific Island Country (PIC)
- cure should be attained at minimal cost of significant late effects – the PIC should not be burdened with caring for cured but significantly disabled survivors of childhood cancer
- cure should be attained without significant financial cost to the PIC
- cancers potentially curable with treatments entirely or predominantly delivered in the PIC
- those children whose cancer is less curable should be treated according to the Palliative Care Guidelines

As expertise and capability and capacity improve,

- can increase intensity protocols and thus improve survival
- can add to the list of good risk cancers

Triage – identifying 'good risk' cancers

1. Acute Lymphoblastic Leukaemia

2. Lymphoma

- Hodgkin lymphoma
- Non-Hodgkin lymphoma
- T-cell non-Hodgkin lymphoma
- B-cell non-Hodgkin lymphoma
- Anaplastic large cell lymphoma

3. Wilms Tumour

4. Retinoblastoma

5. Germ cell tumours

Most cases, even those with metastases, are very curable with a combination of chemotherapy and surgery.

6. Acute Promyelocytic Leukaemia: provided ATRA available

7. Hepatoblastoma: non-metastatic cases *with a strong likelihood of resection* (pretext stages 1, 2 and 3)

8. **Neuroblastoma-**

Stage 1 and 2 neuroblastoma is treatable.

Unresectable, localized neuroblastoma in an infant is readily curable with non-intensive chemotherapy and surgery.

Most stage 3 and all stage 4 disease should receive palliative care

9. **Soft Tissue Sarcoma (Stage 1 and 2 disease)**

10. Bone tumours- Osteosarcoma and Ewings sarcoma require complex multimodality care-maybe inappropriate to offer treatment in these patients. Amputation only may be an option in some- as long as prosthesis available.

11. Brain tumours – only those curable with surgery +/- radiotherapy

Most cases should not be offered anti-cancer therapy. However, some are curable with surgery alone; if such a case is confidently identified, it would be reasonable to offer neurosurgery.
Germinoma (non-secretory intracranial germ cell tumour) in an adolescent is readily curable with radiotherapy only and should be considered for treatment.

- *these are guidelines*

- each case should be considered on its individual merits

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Treatment Protocols

- Acute Lymphoblastic Leukaemia (ALL)
- Acute Promyelocytic Leukaemia
  - (APML -Fiji only if ATRA available)
- Hodgkin's lymphoma
- Wilms tumour
- Germ cell tumour

Supportive Care Guidelines

- Blood product support
- New Patient assessment
- Blood produce support
- Cytotoxic administration
- Drug dosages
- Emergencies
- Infection recognition and management
- Symptom control
- Palliative care

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Training/Education

Treatment Childhood Cancer

Effective treatment of cancer relies on:

- Early detection- Early warning signs of childhood cancer
- Accurate diagnosis
- Access to surgery, chemotherapy and/or radiotherapy
- Access to supportive care
- Parent support organisations

Early Warning signs

Ngaahi faka’ilonga fakatokanga ‘o e Kanisa ‘i he Fanau

SEEK	**Kumi** fale’i mei he toketa ‘o ka fuoloa ho’o ongo’i puke
EYE	**Fofonga** ‘asi me’a hinehina he tama’uli, tepa e mata, kui pe fo’i mata hopo
LUMP	**Fakafefeka pe fufula** he kete, ulu, kia, fakatangata, alanga, uma, nima pe va’e pe ko ha lama
UNEXPLAINED	**‘Ikai ha ‘uhinga lelei** ki he mofi, holo e mamafa, ta’efiefiekai, mata tea, tavaivaia, taka’uli, fetoto’i ngofua pe tu’u ngata’a ‘ae toto
ACHING	**Langa** hui, hokotanga hui, tu’a pe fasi ngofua ‘a e hui
NEUROLOGICAL SIGNS	**Liliu** ‘ulungaanga maheni, palanisi ‘e ‘alu, makamaile ‘oe tupulaki ‘ae fanau, fa’a langa’ulu pe tupu folahi fo’i ‘ulu

CONTACT

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CHILD CANCER
Petani House, Fanga, Tonga.
Phone 676-24636

Child Cancer Foundation for Tonga in collaboration with

National Child Cancer Network Pacific Working Group

Developed and Printed by Child Cancer Foundation

Ulua’i Faailoilo o le Gasegase o le Kanesa i Tamaiti

SEEK	**Saili** Faavavevave ona saili se feasoasoani mai le auaunaga faa-le soifua maloloina pe a vaaia auga pei ona taua i lalo
EYE	**Fofoga** Iloilo fofoga o tamaiti mo ila pa’epa’e, sesepa, tauaso, pe fulafula
LUMP	**Patupatu i le Tino** Fula po o se patupatu I totonu o le manava, le ulu, le ua, ma tōtōgasā o alii
UNEXPLAINED	**Lemailoa** Fiva, alualu malie atu lava le tino ma le le fia ‘ai, sesega, vaivai, totolia gofie le tino ma piliki gofie
ACHES	**Tiga Ponaivi** Tiga ponaivi ma so’oga o ponaivi, le tua, ma le ma’ale’ale o ponaivi
NEUROLOGICAL SIGNS	**Fai’ai ma le Mafaufau** Suiga va’aia o le amio ma aga, le savali, tiga le ulu, po o le lapo’a ese o le ulu

Samoa Cancer Society Inc. 1998

in collaboration with

Developed and Printed by Child Cancer Foundation

National Child Cancer Network Pacific Working Group

Early Warning Signs

C CONTINUED, UNEXPLAINED WEIGHT LOSS
lutu tikoga ni yago ka sega ni macala na vuna

H HEADACHES, OFTEN WITH EARLY MORNING VOMITING
mosi ni ulu sala vata kei na lualua e na mataka lailai

I INCREASED SWELLING OR PERSISTENT PAIN IN BONES
vuvuce ni liga kei na yava, kei na momosi ni sui

L LUMP OR MASS ESPECIALLY, NECK, STOMACH
vuce ni qirimo e na loma ni kete se e na domo

D DEVELOPMENT OF UNUSUAL BLEEDING, BRUISES/RASH
dabuiloa ni kuli kei na ucu ucu kalavo, dra ni vunibatida

C CONSTANT ILLNESS
dau tauvimate vakawasoma

A A WHITISH COLOUR IN THE EYE
vulavula mai na loa ni yaloka ni mata

N NAUSEA/VOMITING
lomaloma ca kei na lualua

C CONSTANT TIREDNESS OR PALENESS
wawale rawarawa se vulaci ni yago

E EYE OR SIGHT CHANGES WHICH OCCUR SUDDENLY AND PERSIST
vakasauri ni buwawa ni mata kei na reva ni mata ka sega ni qai vinaka tale

R RECURRING AND PERSISTENT FEVER
yaco veitaratarovi na katakata ni yago ka sega ni macala na cava e vakavuna

**GO NOW TO YOUR NEAREST HEALTH FACILITY
IF YOUR CHILD HAS ANY ONE OF THE ABOVE**

Early Warning Signs

C CONTINUED, UNEXPLAINED WEIGHT LOSS
Lagataar wazaan ka ghatna

H HEADACHES, OFTEN WITH EARLY MORNING VOMITING
Hamesha sar mein dard rahena; subha subha ulti hona

I INCREASED SWELLING OR PERSISTENT PAIN IN BONES
Adhik sujan ya lagataar hadion mei dard hona

L LUMP OR MASS ESPECIALLY, NECK, ABDOMEN
Gale ya peth mein gaath baandhana ya sujan hona

D DEVELOPMENT OF EXCESSIVE BLEEDING/RASH
Kharoch hona, phunsi ka ubharna aur asamanya khoon nikalna

C CONSTANT INFECTIONS
Niyat roop se aswasth rahena

A A WHITISH COLOUR IN THE EYE
Aankhon mein safedi aana

N NAUSEA OR VOMITING
Ulti ya ubkaai aana

C CONSTANT TIREDNESS OR NOTICEABLE PALENESS
Har waqt thakaan mahesus karna aur nazar aanewali pila pan hona

E EYE OR VISION CHANGES WHICH OCCUR SUDDENLY AND PERSIST
Aankho mein ya dekhne mei takleef hona ya badlaao aana jo bana rahega

R RECURRENT AND PERSISTENT FEVER OF UNKNOWN ORIGIN
Lagataar bukhaar lagna

**GO NOW TO YOUR NEAREST HEALTH FACILITY
IF YOUR CHILD HAS ANY ONE OF THE ABOVE**

Gains

- NGOs supporting parents in Tonga, Samoa and Fiji

- Launch Early warning signs in Samoa, Tonga and Fiji

- Development PI ALL#2 protocol – more intensive
- November 2015 Tonga- TMA- focusing on cancer and looking to progress made in childhood cancer

- 2015- presentation Fiji "National Paediatric Oncology plan" to MOH
- Proposal submitted to Fiji MOH for funding (by WCCCT) of a community nurse based at Lautoka Hospital, with vehicle – to be the link between hospital and the community for the families

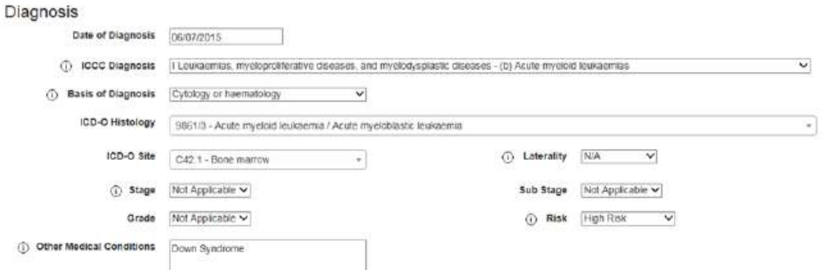
Gains

- Demonstrated significant ownership and in country buy-in for continuation of our initiative- sustainability with twinning

- Gradual increased capability and capacity
- Ripple effect of improving care for children with cancer impacts of care of other sick children: e.g. nursing , laboratory, pharmacy
- Tonga and Fiji using PI ALL#2 protocol – more intensive
- Development of an integrated Pacific Children's Cancer Registry
- Ongoing training and education: in-country, regionally or in NZ

Pacific Child Cancer Registry

- National data collection is essential in order to monitor access to child cancer services and to measure improvements in survival and quality of life outcomes.
- Recognising the need for timely and accurate data on the diagnosis treatment, survival and outcome of childhood cancer; the Pacific Working Group and World Child Cancer Charitable Trust have supported the development of a Pacific Children's Cancer Registry (PCCR)
- Web based with data fields as for NZCCR
- Coding as per ICCC-3 and ICD-O-3



Diagnosis

Date of Diagnosis: 06/07/2015
ICCC Diagnosis: I Leukaemias, myeloproliferative diseases, and myelodysplastic diseases - (b) Acute myeloid leukaemias
Basis of Diagnosis: Cytology or haematology
ICD-O Histology: 9861/3 - Acute myeloid leukaemia / Acute myeloblastic leukaemia
ICD-O Site: C42.1 - Bone marrow
Laterality: N/A
Stage: Not Applicable
Sub Stage: Not Applicable
Grade: Not Applicable
Risk: High Risk
Other Medical Conditions: Down Syndrome

- Aim to 'gift' to Tonga, Samoa, Vanuatu and Fiji so they can enter and manage their own data

Where it is working well

- Identified clinical and political champions
- Alignment with the country’s health plan and now SDG
- Rational referral to NZ for confirmed diagnosis and initiation of reduced intensity therapy as per triage guidelines
- Repatriation early for ongoing treatment with support from Starship, NZ
- Palliation for those not receiving curative treatment
- Viable service with parent support group established alongside clinical expertise

Where are we at 10 years post?

- Tonga, Samoa, Fiji and more recently Vanuatu
- Improvement ascertainment of cases in Fiji, Samoa and Vanuatu
- 100% ascertainment in Tonga
- Increasing number of survivors of child cancer- who have completed treatment
- Less abandonment of therapy
- Request for Paediatric Palliative Care training

Other Pacific countries:

- Relationship now with RCH Melbourne with PNG, Solomon's, East Timor whilst Children's Hospital at Westmead, Sydney have had a longstanding arrangement with New Caledonia

Challenges

Geography and Natural disasters in the Pacific

Samoa	29 September 2009	-Tsunami
Samoa	13 December 2012	-Cyclone Evan
Vanuatu	13 March 2015	-Cyclone Pam
Fiji	20 February 2016	-Cyclone Winston
Samoa	9 February 2018	-Cyclone Gita
Tonga	12 February 2018	-Cyclone Gita

- May result in changes in priorities and reallocation of funding

Challenges

- Late referrals/ late diagnosis (traditional healers)
- Making the correct diagnosis
- Review of imaging, histology- transfer of data
- Abandonment of treatment
- Pharmaceuticals- regular supply of reliable, affordable medications- iincluding anticancer medicines
- Medical and Political champions
- Leadership/ mentorship and sustainable workforce
- Succession planning
- Ongoing training and education

Challenges

- Maintaining expertise with core group Drs and nurses with small numbers of patients
- Role of multidisciplinary team and NGOs
- Ongoing funding to send 'good risk cancers' out of country to NZ:Tonga, Samoa, Vanuatu to SSH and Fiji to CHOC or SSH as indicated – imaging, specialist surgery, radiotherapy
- Palliative Care for those not deemed good risk- seeking traditional / custom medicine and then not engaging with health system
- Meeting families expectations that some cancers will not be offered curative treatment (i.e. not deemed good risk cancer)

Challenges

- How to increase capacity and capability
- Implementing increasing intensity of treatment protocols
- Just because cytotoxic agent is included on the EML- doesn't necessarily mean it can be given in every country.
- Need to ensure that the:

"other essential components of the overall treatment package, such as transfusion support, adequate nursing, pharmacy and laboratory resources or surgical infrastructure, …..without which chemotherapeutic agents may be futile at best or dangerous at worse."

Gupta S, *Pediatr Blood Cancer 2015; 62: 1685-1686*

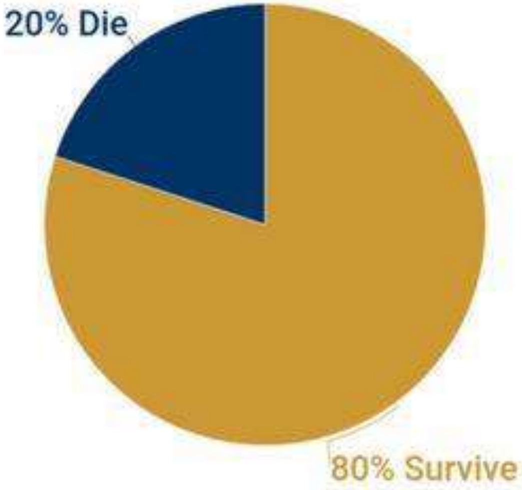
Issues reported internationally

- Late or non-diagnosis
- Treatment refusal
- Treatment toxicity on protocols considered standard in developed health systems
- Procurement anti- cancer medication
- Treatment abandonment due to expense and family dislocation
- Failure when project not driven locally
- Hospital detention (Africa, Asia, Latin America and Eastern Europe)
  - *SIOP PODC Global Taskforce*

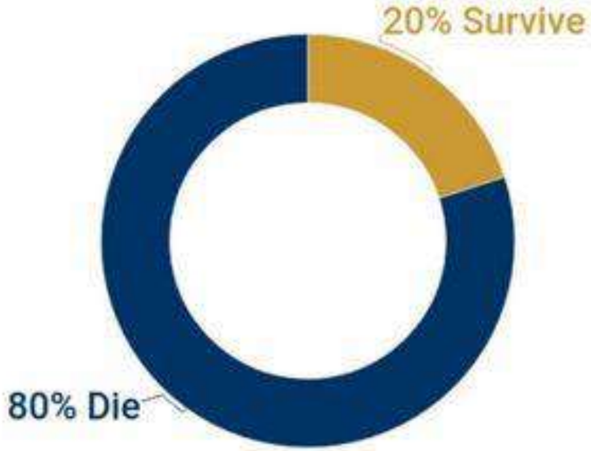
Global Agenda
Advocating for Children with Cancer

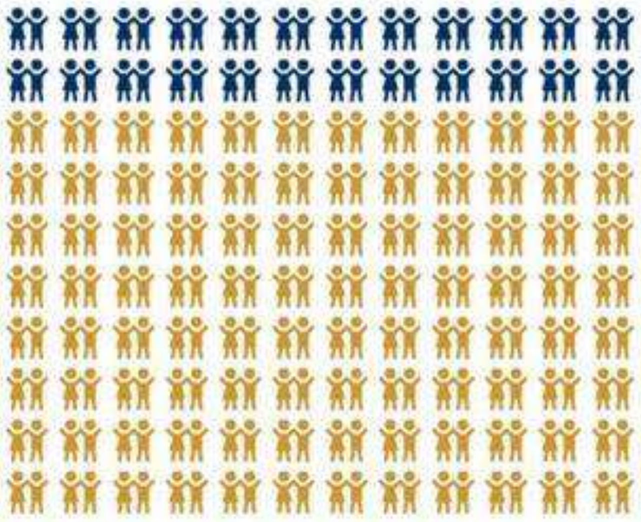
Role SIOP, CCI, WHO

Childhood Cancer 5 Year Survival in Developed Countries



Childhood Cancer 5 Year Survival in Low-Middle-Income Countries





80% of all children with cancer live in low-middle-income countries

SIOP 2018
INTERNATIONAL SOCIETY OF PAEDIATRIC ONCOLOGY
KYOTO, JAPAN I NOVEMBER 16-19, 2018

INDIGENOUS PEOPLE AND CANCER
A shared agenda for Aotearoa, Australia and Pacific nations

SOCIÉTÉ INTERNATIONALE
D'ONCOLOGIE PÉDIATRIQUE
SIOP
INTERNATIONAL SOCIETY
OF PAEDIATRIC ONCOLOGY

Vision: That no child should die of cancer

Aim: To improve and optimise treatments throughout the world

- All children should have access to state of the art outcomes
- All children diagnosed with cancer in the world deserve a right to access to essential medicines and quality care

- Is this achievable?
- What needs to happen for this to occur?

SOCIÉTÉ INTERNATIONALE
D'ONCOLOGIE PÉDIATRIQUE
SIOP
INTERNATIONAL SOCIETY
OF PAEDIATRIC ONCOLOGY

In **2012** SIOP reached out to WHO to collaborate on developing a cooperative action for childhood cancer globally

In **2013** Childhood Cancer International (CCI) joined the WHO collaboration

2015 at WHA, WHO member states organise an event on childhood cancer

31st January 2018 SIOP becomes **non- state actor with WHO**

To place the fight against Childhood and Adolescent Cancer on the global agenda

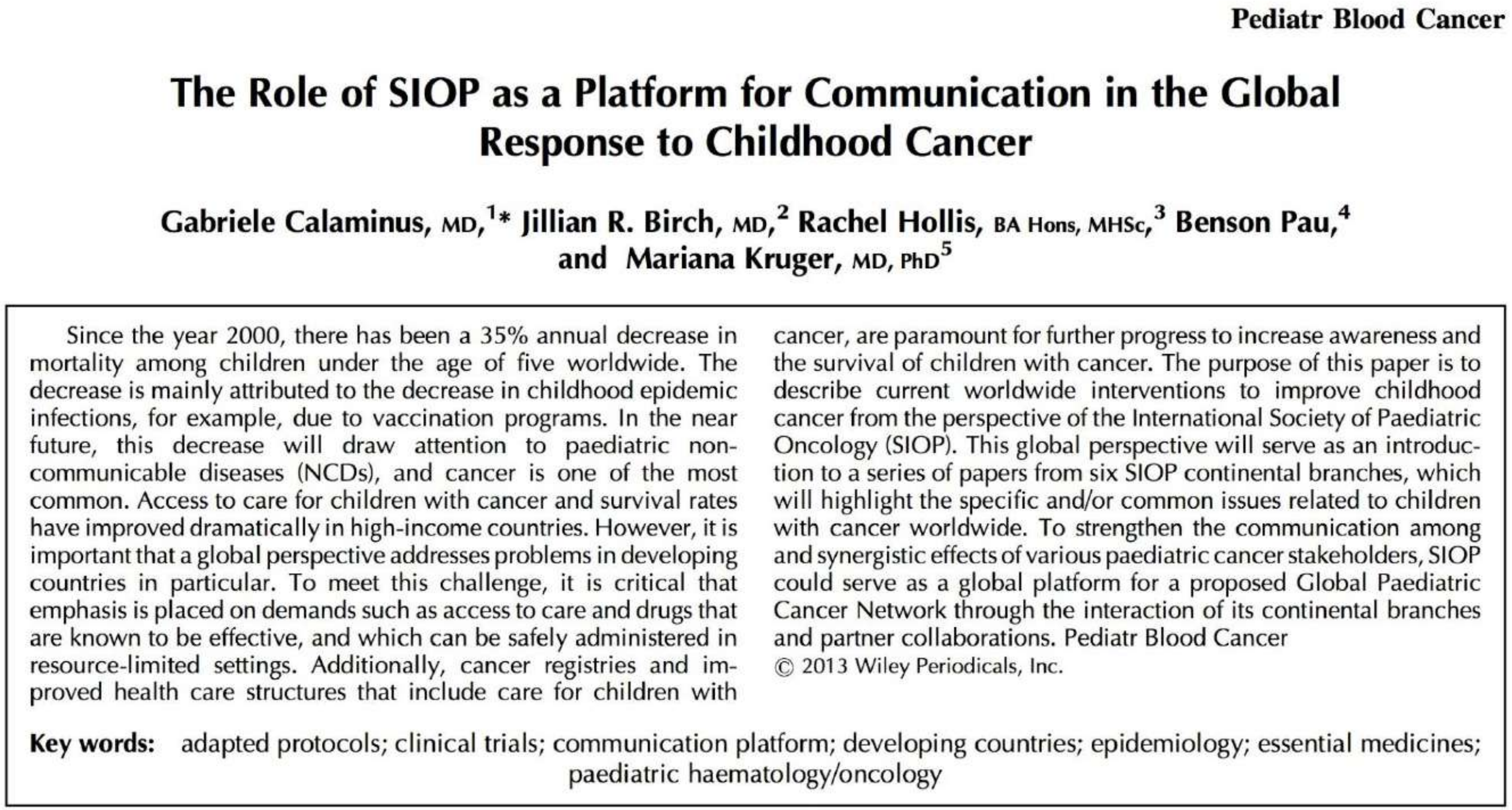
To make a difference in the lives of children with cancer and their families worldwide

The announcement was made by the 142nd Session of the Executive Board of WHO.

WHO engages with non-State actors who are regarded as playing a significant role in the advancement and promotion of global public health.

***SIOP** and **CCI** join renowned organizations including the Bill & Melinda Gates Foundation, International AIDS Society, International Association for Hospice and Palliative Care Inc., Oxfam, Rotary International, Union for International Cancer Control and others.*

Caring for Children and Young People with cancer in Resource Challenged Countries



Pediatr Blood Cancer

The Role of SIOP as a Platform for Communication in the Global Response to Childhood Cancer

Gabriele Calaminus, MD,[1]* Jillian R. Birch, MD,[2] Rachel Hollis, BA Hons, MHSc,[3] Benson Pau,[4]
and Mariana Kruger, MD, PhD[5]

Since the year 2000, there has been a 35% annual decrease in mortality among children under the age of five worldwide. The decrease is mainly attributed to the decrease in childhood epidemic infections, for example, due to vaccination programs. In the near future, this decrease will draw attention to paediatric non-communicable diseases (NCDs), and cancer is one of the most common. Access to care for children with cancer and survival rates have improved dramatically in high-income countries. However, it is important that a global perspective addresses problems in developing countries in particular. To meet this challenge, it is critical that emphasis is placed on demands such as access to care and drugs that are known to be effective, and which can be safely administered in resource-limited settings. Additionally, cancer registries and improved health care structures that include care for children with cancer, are paramount for further progress to increase awareness and the survival of children with cancer. The purpose of this paper is to describe current worldwide interventions to improve childhood cancer from the perspective of the International Society of Paediatric Oncology (SIOP). This global perspective will serve as an introduction to a series of papers from six SIOP continental branches, which will highlight the specific and/or common issues related to children with cancer worldwide. To strengthen the communication among and synergistic effects of various paediatric cancer stakeholders, SIOP could serve as a global platform for a proposed Global Paediatric Cancer Network through the interaction of its continental branches and partner collaborations. Pediatr Blood Cancer

Key words: adapted protocols; clinical trials; communication platform; developing countries; epidemiology; essential medicines; paediatric haematology/oncology


JOURNAL OF CLINICAL ONCOLOGY | REVIEW ARTICLE

Global Pediatric Oncology: Lessons From Partnerships Between High-Income Countries and Low- to Mid-Income Countries

Raul C. Ribeiro, Federico Antillon, Francisco Pedrosa, and Ching-Hon Pui


JOURNAL OF CLINICAL ONCOLOGY | REVIEW ARTICLE

Toward the Cure of All Children With Cancer Through Collaborative Efforts: Pediatric Oncology as a Global Challenge

Carlos Rodriguez-Galindo, Paola Friedrich, Patricia Alcasabas, Federico Antillon, Shripad Banavali, Luis Castillo, Trijn Israels, Sima Jeha, Mhammed Harif, Michael J. Sullivan, Thuan Chong Quah, Catherine Patte, Ching-Hon Pui, Ronald Barr, and Thomas Gross

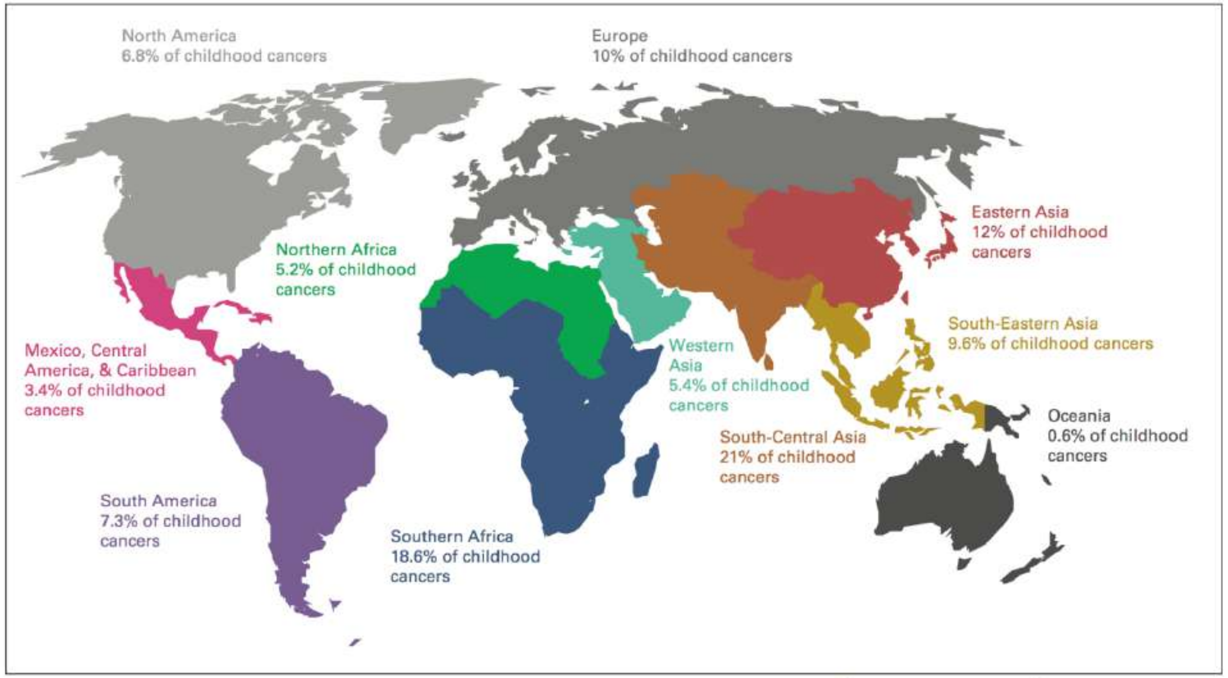


Fig 1. Global distribution of childhood cancer by region. Source: World Bank Databank[10] and GLOBOCAN 2012.[11]

INDIGENOUS PEOPLE AND CANCER

A shared agenda for Aotearoa, Australia and Pacific nations

SIOP PODC Working group
(Paediatric Oncology in Developing Countries)

Mission: to develop, adapt implement and improve treatment regimes for children with cancer in LMIC

- Adapted treatment regimens
- Childhood cancer treatment regimens adapted to local conditions provide an opportunity to cure as many children as possible with the available resources, while working to improve services and supportive care.

What happens when HIC protocols used in LMIC ?

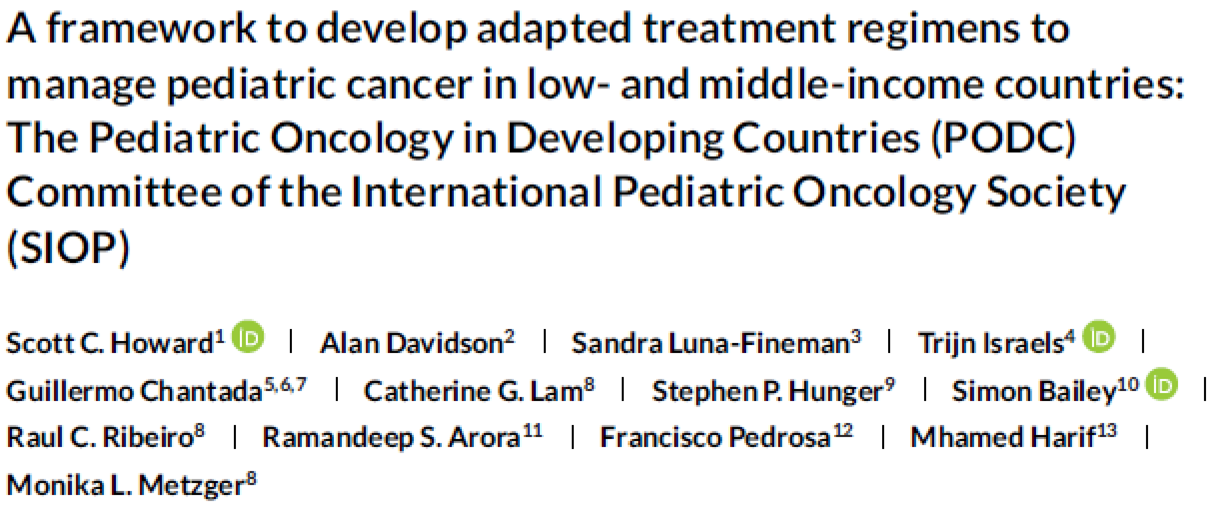
- Total XI protocol for childhood ALL 72 % EFS (USA), but when implemented in Recife, Brazil EFS 32%

Howard SC et al. *JAMA 2004;291:2471-2475*

When protocol adapted (anthracycline removed) in El Salvador

- EFS went from <10 to 48%
- but toxic death rate 48% in induction and another 4.6% in remission
- therefore need to identify where to make improvements, such as **supportive cares**

Bonilla M et al. *J Pediatr Hematol Oncol. 2000;22:495-501*



A framework to develop adapted treatment regimens to manage pediatric cancer in low- and middle-income countries: The Pediatric Oncology in Developing Countries (PODC) Committee of the International Pediatric Oncology Society (SIOP)

Scott C. Howard[1] | Alan Davidson[2] | Sandra Luna-Fineman[3] | Trijn Israels[4] | Guillermo Chantada[5,6,7] | Catherine G. Lam[8] | Stephen P. Hunger[9] | Simon Bailey[10] | Raul C. Ribeiro[8] | Ramandeep S. Arora[11] | Francisco Pedrosa[12] | Mhamed Harif[13] | Monika L. Metzger[8]

Requirements for ATR in LMIC (Levels 0-4)

- Many children with cancer live in low and middle income countries are treated in hospitals lacking key infrastructure, including:
- Diagnostic capabilities
- Imaging modalities
- Treatment components
- Supportive Care and personnel

Choosing the Optimal therapy depends on the setting/level of care

- Also minimal levels of each service line needed to safely

deliver ALL adapted regimens

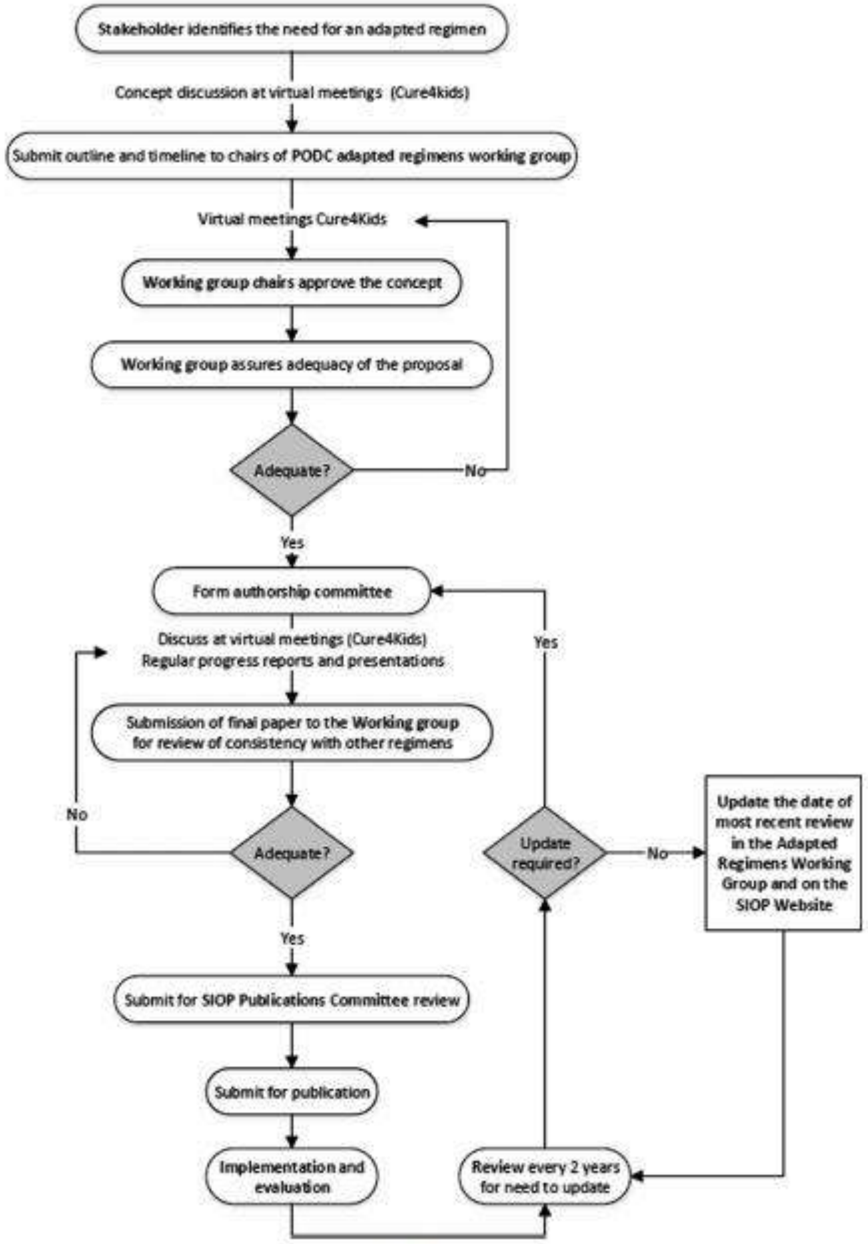


FIGURE 1 Process flow diagram for development of SIOP PODC adapted treatment regimens

Summary- Pacific Island Project

1. Partnership not paternalism
2. Collaboration not control
3. Strength based rather than deficit focused
4. Solution focused rather than problem focused

Future

- Ongoing training of Pacific doctors and nurses with credentialing for Pacific nurses
- Audit/evaluation- clinical outcomes, local capacity, including audit of specimen preparation and transfer/imaging transfer
- Updating of protocols (version #2 as indicated) /guidelines
- Addition of new protocols for other cancers
- Assistance in expanding local availability cytotoxics to include those recommended PODC Formulary "Essential list" with a disease-based approach

Robertson J et al. *Pediatr Blood Cancer 2015; 62: 1689-1693*

- Pacific Child Cancer registry functional in each country ?Tonga to pilot
- Web-based availability guidelines/protocols (SSH /NCCN)

NCCN Pacific Working group (2018)

- **Dr Jane SKEEN**
- **Dr Scott MACFARLANE**
- **Dr Lochie TEAGUE**
- **Dr Peter BRADBEER**
- **Bridget SMITH**

Starship Blood and Cancer Centre, Starship Children's Hospital, Auckland

- **Dr Rob CORBETT**
- **Rachel WILSON**

Children's Haematology Oncology Centre, Christchurch Hospital, Christchurch

- **Dr Michael SULLIVAN** formerly Christchurch, now RCH Melbourne

- **Simon LALA ONZM**

Child Cancer Foundation (CCF)-Life member and former board member and Chair

Chair The World Child Cancer Charitable Trust NZ (WCCCT),

Board member World Child Cancer (WCC) and Children's Cancer International

- **Janet MASINA**

Child Cancer Foundation, Practice Leader- Family Support

NationalChild CancerNetwork NZ
Linking Care / Sharing Knowledge / Advancing Best Practice

Funding for visits 2010-present

- NZ Aid VMS (visiting medical specialists) to the Pacific
- RACS (College Surgeons -PIPS)
- World Child Cancer Charitable Trust NZ

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- National Child Cancer Network
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- The World Child Cancer Charitable Trust
- Child Cancer Foundation NZ and Tonga
- Samoa Cancer Society
- Fiji Cancer Society and WOWS Fiji
- Children with cancer and their families

Child cancer FOUNDATION

NationalChild CancerNetwork NZ
Linking Care / Sharing Knowledge / Advancing Best Practice

The World Child Cancer Charitable Trust