



Improving care for haematological malignancy patients in Latin America

2018

KPMG LLP (UK)



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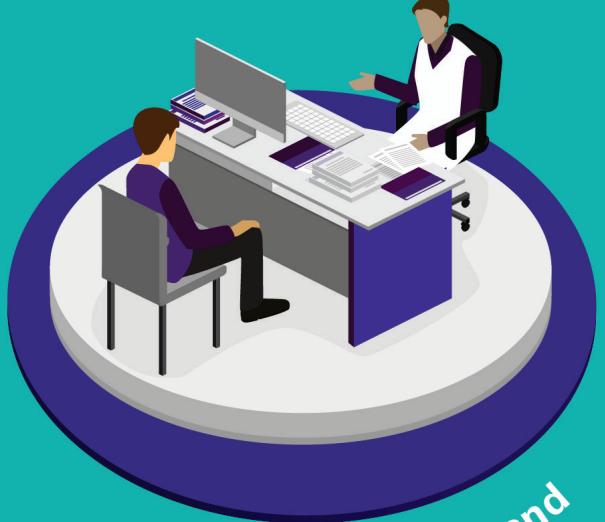
	1 Acknowledgements <ul style="list-style-type: none">— To highlight centres and patient groups who have contributed to this report.
	2 Executive summary <ul style="list-style-type: none">— To provide a summary of the project and findings on good practice care in haematological malignancies.
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	5 Challenges in haematological malignancy care <ul style="list-style-type: none">— To share current challenges in delivering good practice care across the region.
	6 Themes of good practice in haematological malignancy care <ul style="list-style-type: none">— To share five themes of good practice that aim to address challenges to care provision.
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The patient journey for haematological malignancy

The journey of patients with acute and chronic haematological malignancies is complex, requiring multiple engagements with healthcare provision. This report assesses good practice across all of these phases, with the aim of collating improvements to the full patient experience.



**Awareness and
incidental finding**



**Diagnosis and
prognosis**



**Medical treatment
and management**



Monitor or
follow-up





1. Acknowledgements



Acknowledgements

We would like to thank the following centres and individuals for their contribution to this initiative.

	Argentina	Brazil	Colombia	Mexico	Uruguay					
Centre	Hospital Universitario Austral Buenos Aires	Fundación Para Combatir la Leucemia (Fundaleu) Buenos Aires	Americas Centro de Oncología Integrado Rio de Janeiro	Instituto do Câncer do Estado de São Paulo Sao Paulo	Clinical Colombia Colsanitas Bogotá	Fundacion Santa Fe de Bogotá Bogotá	Instituto Nacional de Cancerología Mexico City	Hospital Regional de Alta Especialidad de Ixtapaluca Mexico City	Hospital Ángele Lomas Mexico City	Hospital Maciel Montevideo
Clinicians and members of Patient Association Groups	Dr. Gustavo Kusminsky	Dr. Miguel Pavlovsky	Dr. Ricardo Bigni	Dr. Vanderson Rocha	Dr. Juan Ospina	Dr. Miriyam Rodriguez Dr Andres Rodriguez	Dr. Eduardo Cervera	Dr. Alvaro Cabrera	Dr. Roberto Ovilla Martinez	Dr. Raul Gabús
ALMA Fernando Piotrowski		ABRALE Merula Steagall		Fundacion leucemia y linfoma Yolima Mendez		Asociacion Mexicana de Lucha Contra el Cancer A.C. Mayra Galindo				

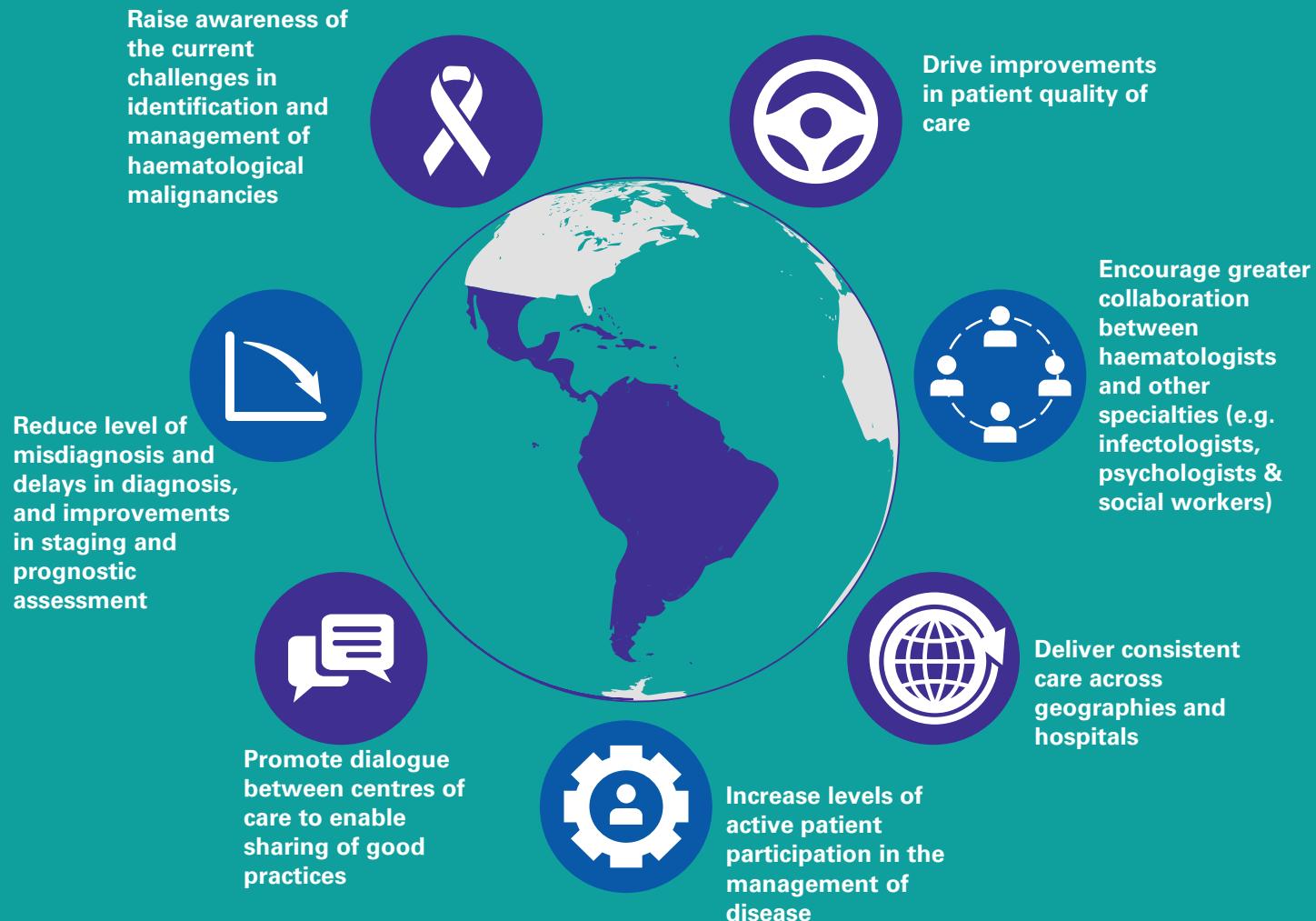


2. Executive summary





This report aims to help improve the management of patients with haematological malignancies in Latin America, and build a more consistent model of care



It is a comprehensive compilation of good practice in management of haematological malignancies, as observed at leading centres from the region and validated by experts

We engaged with patient association groups throughout the project and they aided us in the selection of ten key centres around Latin America.

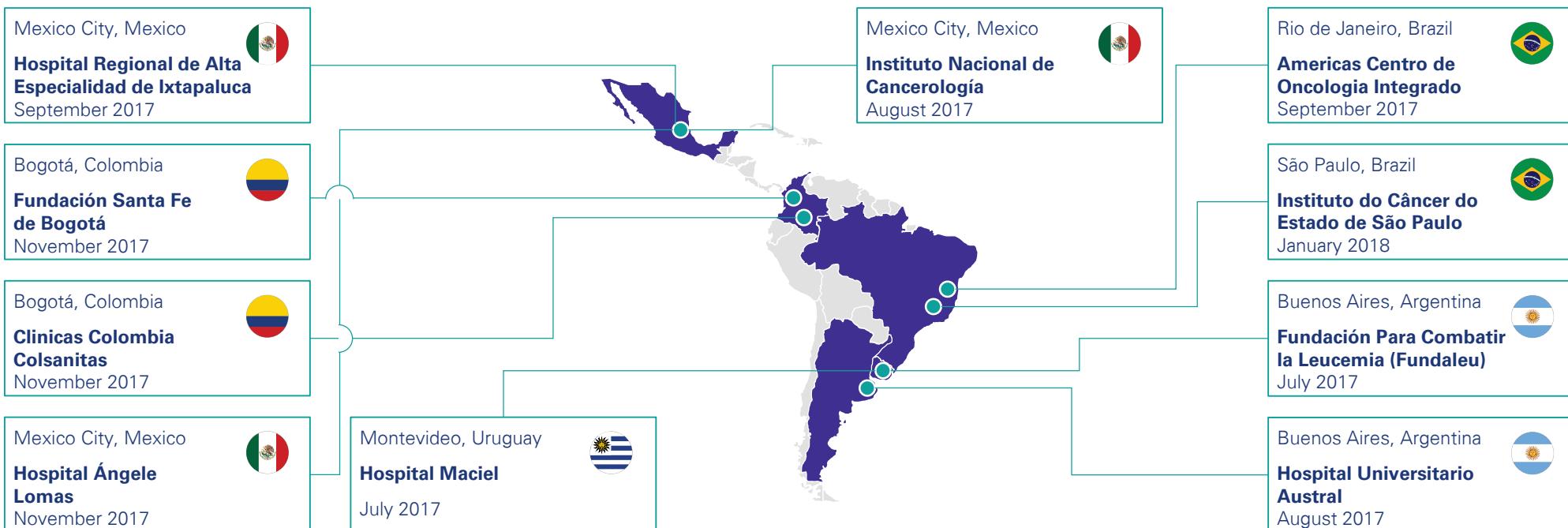
Centres were selected from across the region, and were representative of the majority of healthcare systems found throughout Latin America.

At each centre, we engaged with a range of stakeholders including haematologists, nurses, palliative and integrative care specialists, social workers and administrative teams.

KPMG gathered views in key areas: challenges involved in care, good practices initiatives to address these, the benefit creation as well as treatment networks and patient-centricity.

The findings, collated in this report, were reviewed by the participating centres to ensure their accuracy and validity. Feedback was also captured from patient association groups.

Participating centres:





It introduces five themes of good practice, 25 enabling initiatives, and supporting case studies to help address challenges faced in the delivery of high-quality care

Our visits identified multiple challenges in improving care

- During our research we found a number of challenges that present barriers to the provision of good practice management and care of patients with haematological malignancies in Latin America.
- These challenges were apparent across the patient pathway and demonstrated consistency across various geographies.
- While many of these result from high level issues, such as lack of funding, or national policy positions, many of them can be, and are being, addressed by a number of good practice initiatives developed by the leading centres in the region.

Components of good practice



Themes encompassing good practice care

5 key themes of good practice haematological malignancy care and management, relevant across the full patient pathway.



(pages 41-47)



Good practice initiatives

25 operational initiatives, collated from common practice across the leading centres visited, that can be replicated to achieve elements of good practice by other centres across the region.



(pages 49-127)



Case studies from leading centres

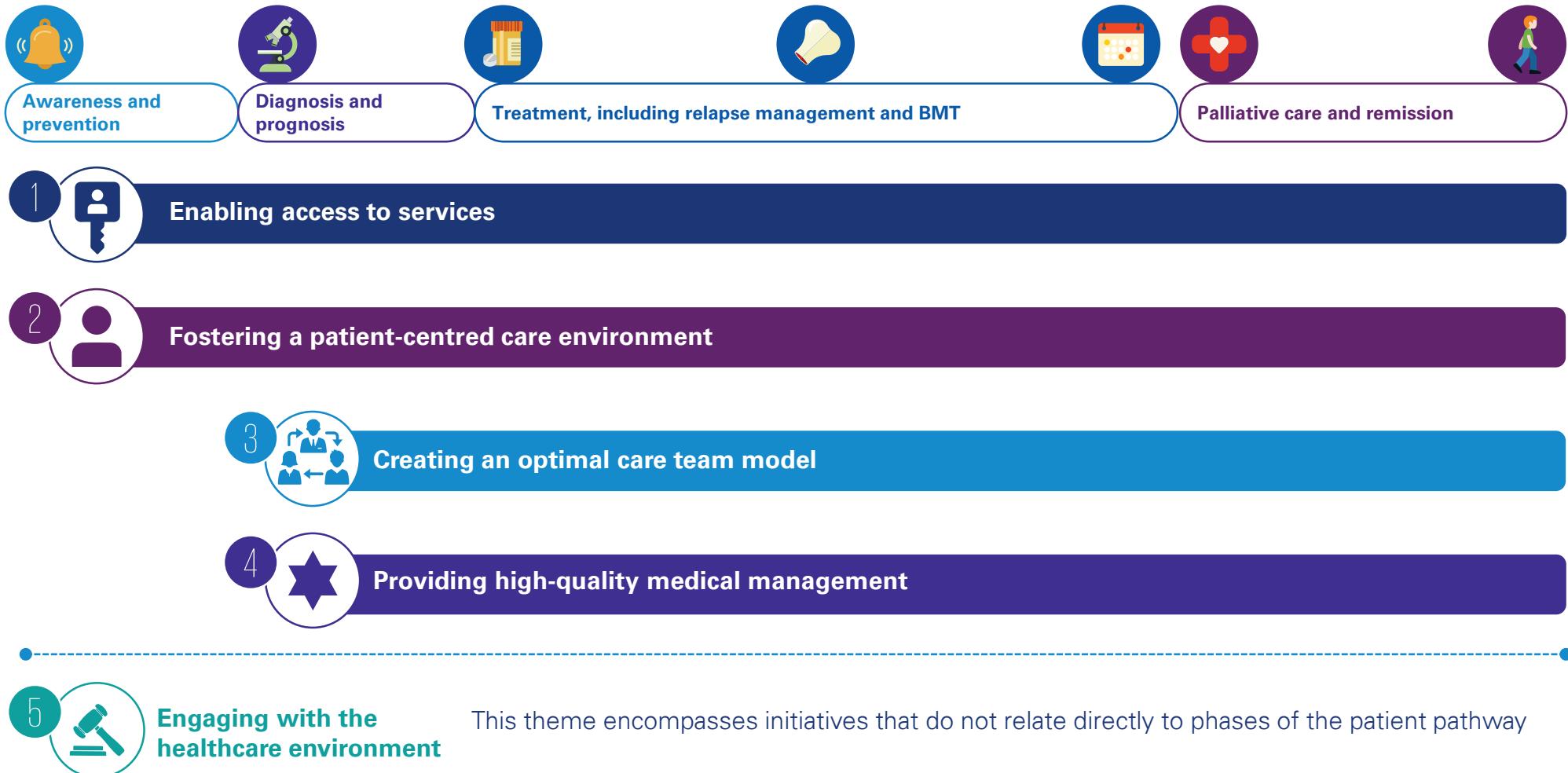
70 case studies detailing rationale, features, resources and potential impact of specific good practice initiatives in place at the leading centres visited.



(pages 129-284)

5 themes, spanning the full patient journey, to identify good practice across the varied care settings for managing haematological malignancies

Themes encompassing good practice:





25 good practice initiatives which underlie the themes, to enable the delivery of consistent and high-quality care to patients

Good practice initiatives:



Enabling access to services



Fostering a patient-centred care environment



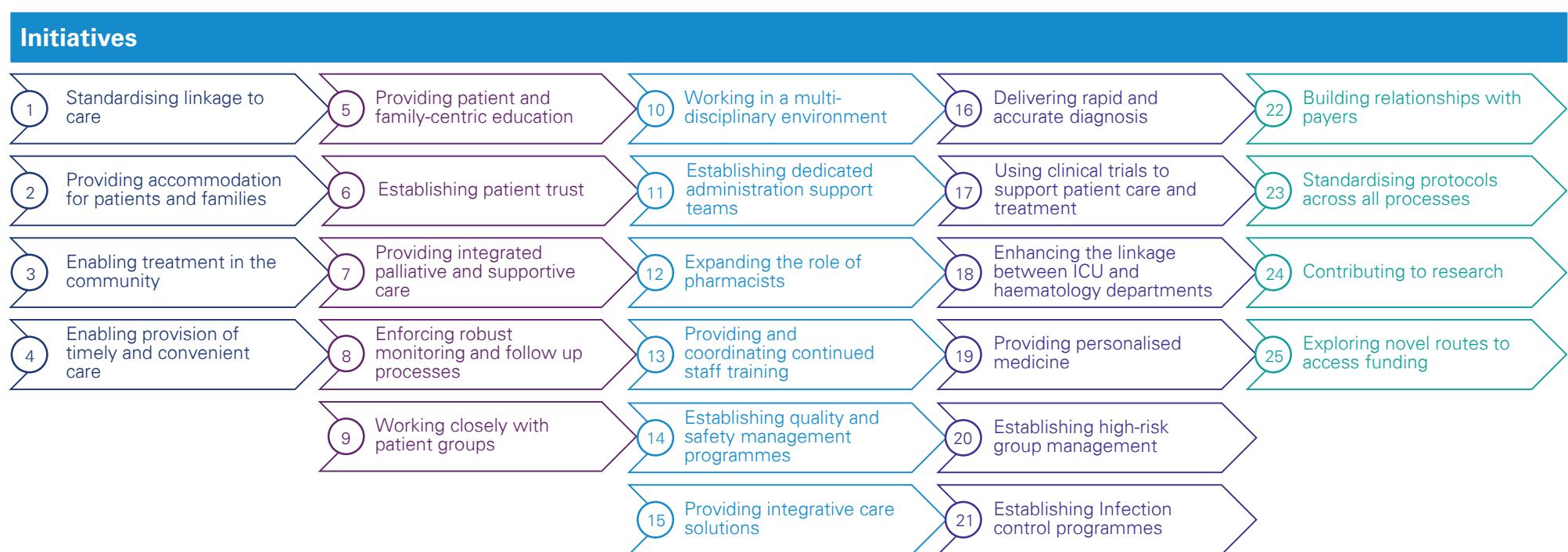
Creating an optimal care team model



Providing high-quality medical management



Engaging with the healthcare environment

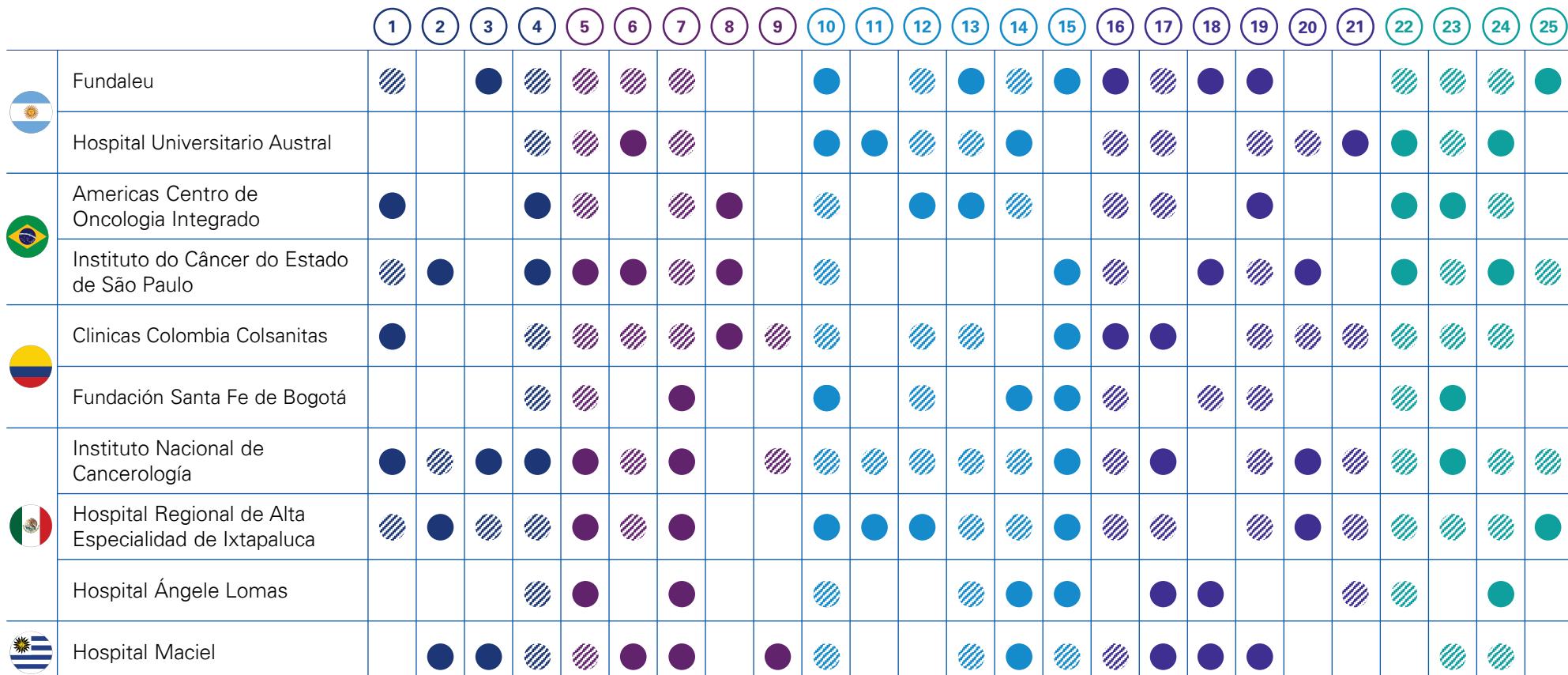


Note: These identified good practice initiatives should not be viewed as isolated activities, as synergies that exist between them can be leveraged to generate a robust platform for a disease management model for haematological malignancies in Latin America (see page 123).

Over 70 case studies, to inspire and inform patients and care teams across the region in specific ways to improve disease management

Initiatives we have seen across the visited centres:

● Selected case studies are available for these initiatives in chapter 8



Key: Themes of good practice initiative observed during observational site visit:

- Enabling access to services
- Creating an optimal care team model
- Engaging with the healthcare environment
- Fostering a patient-centred care environment
- Providing high-quality medical management



3. Background to the project





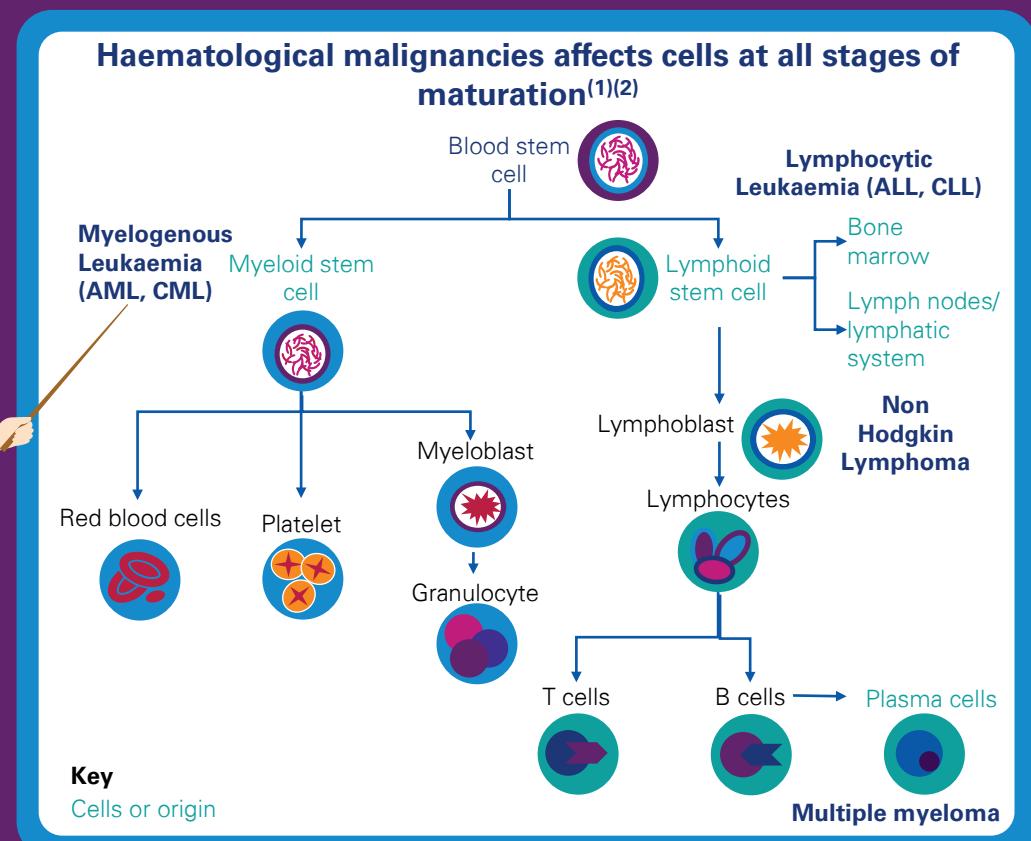
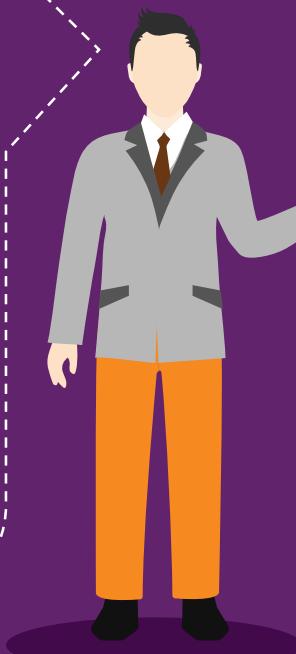
Haematological malignancies encompass a wide ranging class of cancers, affecting the blood, bone marrow and the lymphatic system

What is Haematological Malignancy?

Haematological malignancies are cancers that affect the blood and lymph system, and form from the blood and lymph cells. This variety of cancers may begin in the bone marrow (i.e. the tissue from which new blood cells form), or in cells of the immune system.

The term haematological malignancies encompasses a wide range of distinct malignancies, traditionally considered in four broad categories:

- Leukaemia;
- Multiple Myeloma;
- Non Hodgkin Lymphoma;
- Hodgkin Lymphoma.



Sources: (1) CIBMTR, 'What are the differences between Leukemia and Lymphoma', accessed 11 Oct. 2017; (2) American Cancer Society, 'What is Multiple Myeloma?', accessed 11 Oct. 2017

There are many symptoms of haematological malignancies, related to the impact of malignancy on bone marrow, lymph nodes, spleen and bone

Due to the wide range of diseases characterised as a haematological malignancy, there are a number of corresponding symptoms that may manifest, dependent on the type and site of the disease. Symptoms of a possible haematological malignancy relate to the effect of the disease on bone marrow function, invasion of the lymph nodes and spleen, destruction of tissues (particularly bone), and hyper-metabolism.

Examples of common symptoms indicating a possible underlying haematological malignancy are below, characterised by disease site.



Bone marrow failure

- Anaemia
 - Breathlessness
 - Fatigue
 - Palpitations
- Thrombocytopenia
 - Easy bruising or bleeding
- Neutropenia
 - Recurrent infections



Increased metabolism

- Weight loss
- Sweating (especially at night time)
- Fever



Splenic enlargement

- Discomfort or pain in the left hypochondrium
- Early satiety (due to reduced stomach capacity)
- Referred pain to the left shoulder (occasional)



Peripheral lymph node enlargement

- Palpable enlarged lymph nodes in the main nodal areas
 - Neck
 - Axillae
 - Supraclavicular fossae
 - Inguinal regions



Bone destruction

- Bone pain (often deep seated and persistent)
- Pain from pathological fracture (e.g. rib pain following coughing)

It is common for patients to be diagnosed with haematological malignancies, who present in an asymptomatic status, with the diagnosis made as a result of incidental findings revealed during routine blood examination.

Source: [Francis Matthey, 'GP guide to the management of haematological malignancies', 12 Oct 2009](#)



While specific causes or risk factors are diverse, there are known factors that may increase the level of risk

All blood cancers are caused by genetic abnormalities. Unlike other cancers, the factors that contribute to blood cancer development are largely things that cannot be controlled such as genetic predisposition, age and an association with high-risk disorders.

The known risk factors for haematological malignancies can be grouped as below:



Genetic syndromes

Genetic syndromes such as Downs syndrome, Fanconi anaemia, Bloom syndrome, Ataxia-telangiectasia, and Diamond-Blackfan anaemia are known to increase the risk of the individual developing some types of haematological malignancy.



Age

Age is the most significant risk factor in haematological malignancies, which occur most often in patients who are more than 60 years old.



Weakened immune system

A weakened immune system and certain infections, such as HIV, can increase the risk of certain non-Hodgkin lymphomas.



Family history

Most cases of haematological malignancies are not thought to have a strong genetic link, although having a close relative with a haematological malignancy can increase the risk. Blood cancers rarely run in families.



Environmental exposure

Exposure to benzene, radiation and certain cancer therapies has been linked to the development of leukaemia:

- Benzene is a solvent used in the rubber industry, oil refineries, chemical plants, shoe manufacturing and gasoline-related industries. It is also found in cigarette smoke, gasoline and motor vehicle exhaust fumes, some glues, cleaning products, detergents, art supplies and paints. There is a weaker correlation between exposure to formaldehyde and Acute Myeloid Leukaemia (AML) risk.
- Chemotherapy containing alkylating agents and platinum agents are linked to an increased risk of AML, which has shown to peak about eight years after chemo. Often this predisposes patients to myelodysplastic syndrome before the AML. Additionally, chemotherapies containing topoisomerase II inhibitors are also linked to AML.
- High-dose radiation exposure is known to increase the risk of developing certain leukaemias, which is seen to peak around six to eight years following exposure. These levels of radiation refer to significant exposures, such as following an atomic bomb blast, or a nuclear reactor accident. The risks associated with low-level radiation exposure, such as from imaging tests like X-rays and CT scans, is not well-defined.

Sources: (1) [American Cancer Society, 'What Are the Risk Factors for Acute Myeloid Leukemia?'](#), accessed 11 Oct. 2017; (2) [Mayo Clinic, 'Leukemia'](#), accessed 11 Oct. 2017

Haematological malignancies represent a significant burden in Latin America, and display varied prevalence and incidence rates across the region

Estimated number of **prevalence** cases (1 year) – both sexes, 2012⁽¹⁾

Leukaemia



Non-Hodgkin lymphoma

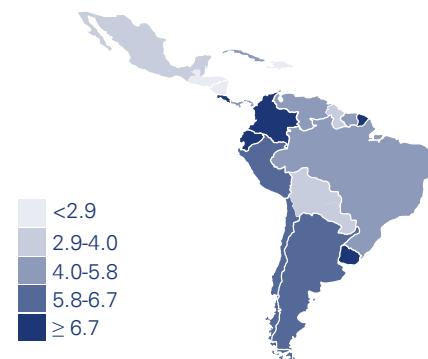
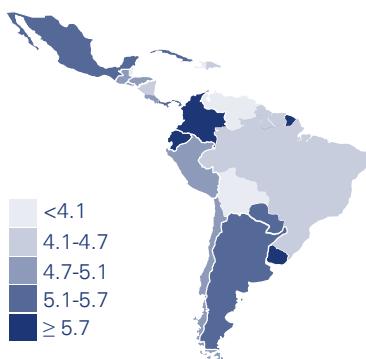


Multiple Myeloma⁽²⁾



Argentina (9.1) and Uruguay (14.3) show the highest prevalence collectively of leukaemia, non-Hodgkin lymphoma and multiple myeloma across the Latin America region.

Estimated number of **incident** cases – Age standardised for both sexes, 2012⁽¹⁾



Uruguay (16.6) and Colombia (14.2) show the highest incidence collectively of leukaemia, non-Hodgkin lymphoma and multiple myeloma across the Latin America region.

Sources: (1) [Cancer Today, 'Explore'](#), accessed 11 Oct. 2017; (2) [Cancer Today, 'Estimated number of prevalence cases \(1-year\), both sexes, multiple myeloma, worldwide in 2012'](#), accessed 11 Oct. 2017

The journey of patients with acute and chronic haematological malignancies is complex, requiring multiple engagements with healthcare provision.





Monitor or
follow-up



Limitations in awareness and specialist training around haematological malignancies leads to delayed diagnosis and prognosis



Awareness/Incidental finding

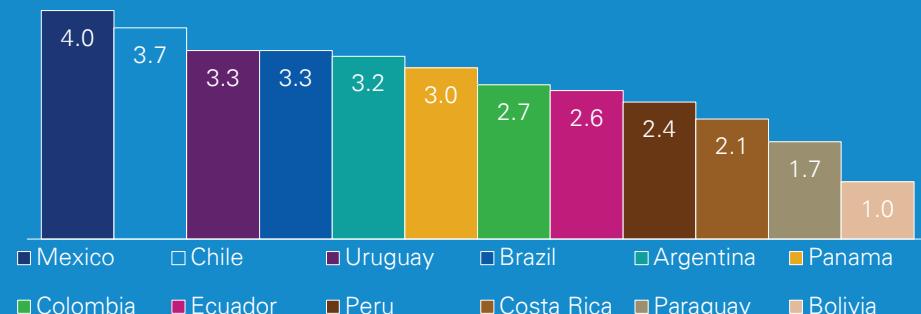
There is a significant issue with lack of awareness of haematological malignancies in Latin America, among both physicians and the wider public. This is manifested as high rate of late-stage diagnosis.

60-70%

of cancer patients are diagnosed at advanced stages of disease.



Prevention & Early Detection focus (2017)



NB A Score of 5 should be read as a sign that the country performs well compared with its peers, not that it is flawless in this area.

Sources: The Economist Intelligence Unit, *Cancer control, access and inequality in Latin America A tale of light and shadow*, 2017; Raul Gabus et al., 'Hematology in Latin America: where are we? Analysis of the reports of Societies of Hematology associated organization of the Highlights of ASH in Latin America', 2011; Nelson Hamerschlak et al., 'Patients' perceptions about diagnosis and treatment of chronic myeloid leukemia: a cross-sectional study among Brazilian patients', 2015; KPMG insight



Diagnosis and prognosis

There is reasonably good coverage for the vast majority of diagnostic techniques across Latin America, however access to prognostic facilities/techniques such as molecular biology is highly variable.

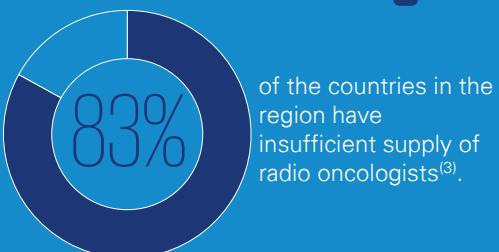
There is a critical shortage of specialists in Latin America. There are only

0.9

haematologists per

100,000

inhabitants⁽²⁾ and



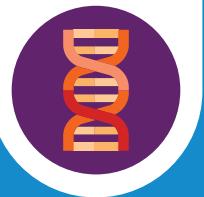
of the countries in the region have insufficient supply of radio oncologists⁽³⁾.

Mexico City has the largest concentration of CT scanners in the world, with regional centres having poor local facilities.

33% of radiotherapy machines in Latin America still used the old cobalt 60 technology in 2013.

Sequencing is essential in accurately depicting a patient's prognosis, however it is not reimbursed across any Latin American country.





The treatment paradigm for haematological malignancies requires specialist facilities to implement novel and complex therapies



Medical treatment & management



Chemotherapy

- Chemotherapy is the standard of care for first and second line treatments in the majority of haematological malignancies in Latin American public healthcare systems.
- There is variation in the reimbursed combinations and regimens of chemotherapy available for use.
- In some instances, funding decisions are made by indication, so availability of chemotherapy is dependent on the patient's diagnosis.
- In the private care setting, use of chemotherapy may be pushed down the treatment paradigm in favour of novel targeted therapies.



Novel targeted therapy

- Novel targeted therapies are slowly gaining approval in across Latin America, however the level of access to these therapies lags far behind that in the US and EU.
- Those therapies which are approved are, in many cases, not reimbursed by public healthcare, and when they are it is further down the treatment paradigm in highly characterised patient subsets.
- Access to novel targeted therapies is tied to the specific arm of the national healthcare system to which the patient belongs.



Bone marrow transplant

- Bone Marrow Transplant is indicated following very high dose chemotherapy regimens and/or extensive radiotherapy.
- Generally it is only performed by a small number of specialist centres throughout Latin America as specific accreditation is required. Consequently access to this therapy is dependent on the referring centre's existing networks.
- Sourcing of material is highly variable, with different centres having different approaches (i.e. autologous; related allogenic; unrelated allogenic; haplo-identical etc.



Radiotherapy

- Haematological malignancies are very sensitive to radiotherapy, and consequently significantly lower doses are required as compared with other malignancies.
- Total body irradiation is often used alongside chemotherapy regimens as part of the transplant preparative regimen, or as part of the conditioning regimen.

Sources: (1) The Economist Intelligence Unit, Cancer control, access and inequality in Latin America A tale of light and shadow , 2017; KPMG insight

The treatment paradigm for haematological malignancies requires specialist facilities to implement novel and complex therapies (cont.)



Medical treatment & management



Slow regulatory approval of novel therapies and lack of coverage by the fragmented public health systems mean that patients often have limited access to these therapies.

30%  of people

lack adequate healthcare coverage in Latin America. Even for people with coverage, out of pocket expense can be as high as

44% in Mexico.

In Mexico, Seguro Popular only covers treatment of lymphomas, leaving leukaemia and myeloma patients without coverage.



The total number of trained specialist oncology nurses in Brazil, meets only **1/2** of São Paulo's needs.



 Only **Uruguay** and **Chile** have enough radiotherapy machines to meet national needs.



2/3 

Rise in the spending by the public healthcare system on cancer surgery, chemotherapy and radiotherapy between 2010-2015.

There are a limited number of centres appropriately accredited to perform bone marrow transplantation, and understanding of eligibility for this procedure is highly variable.



4.8% 

of cancer patients in Brazil used the courts to obtain medication in the second half of 2014.

Sources: (1) The Economist Intelligence Unit, 'Cancer control, access and inequality in Latin America A tale of light and shadow', 2017; KPMG insight;



There is low integration of palliative care into the treatment pathway, and limitations in access



Palliative care

In much of Latin America, access to palliative care is significantly limited, and where it is available, it is rarely effectively integrated into the healthcare system, and is often delivered to the patient too late in their treatment.



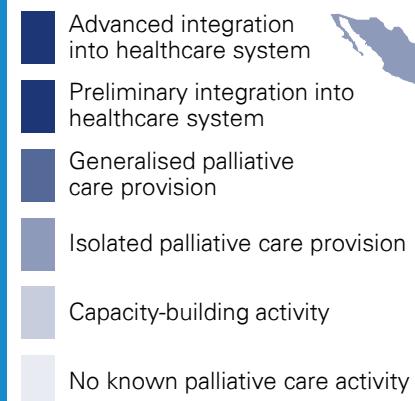
4 Latin American countries have official palliative care accreditation as a medical speciality.



Palliative care is rarely implemented as early as WHO recommendations, due to poor integration.



Full palliative care services per 1m population



30% of palliative care services in Latin America are located in Chile.

Most haematological malignancy patients will require palliative care at some point during their care.

Patients have access to palliative care in the major cities in Mexico, however in rural and even suburban areas, access to palliative care is quite limited.



Radiotherapy availability in public health system is poor in Brazil, Mexico and Colombia, and late diagnosis within the region makes radiotherapy important for palliative care.

Sources: (1) The Economist Intelligence Unit, *Cancer control, access and inequality in Latin America A tale of light and shadow*, 2017; KPMG insight;



4. The project

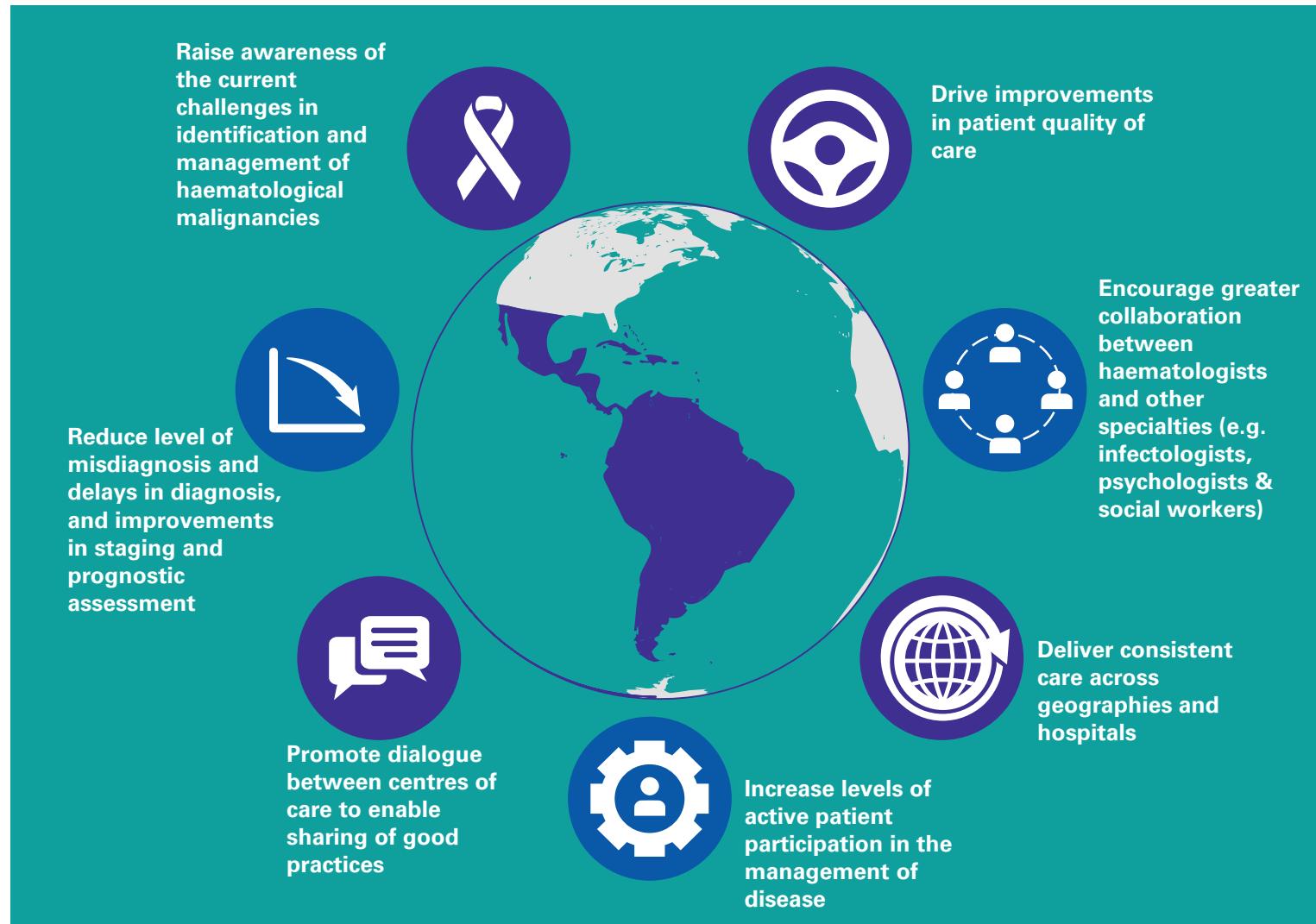


The goal of this project is to improve the quality and efficiency of haematological malignancy care throughout Latin America

The goal was to learn from leading centres in the region good practice initiatives that improve the care of patients with haematological malignancies.

As part of this, we brought together experts (chief haematologists from the leading centres, regional experts, patient association group representatives), to create an engaged network who will drive the implementation of these improvements across the continent.

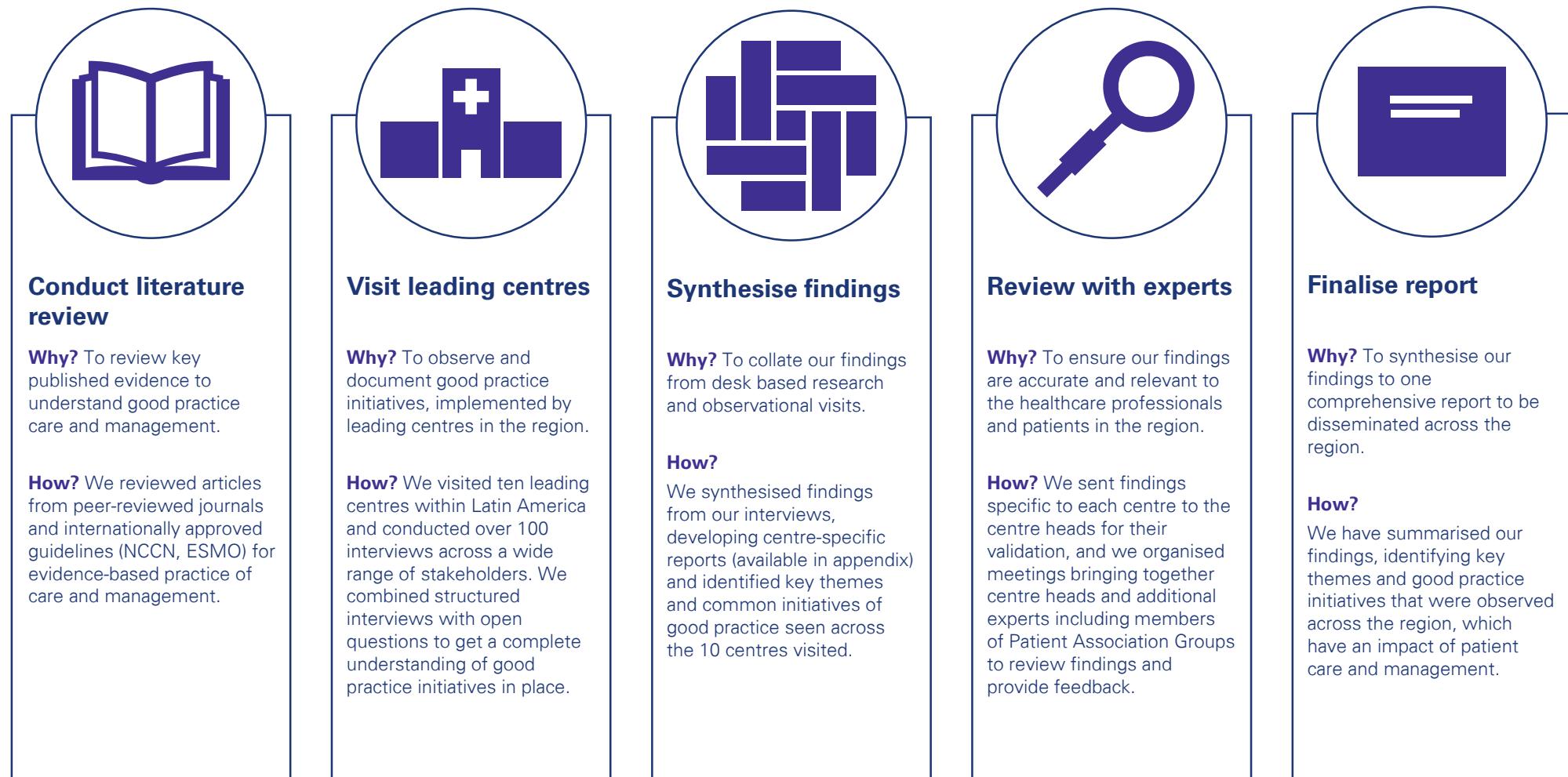
By doing this, we aimed to help build a more reliable and consistent model of care for patients suffering from haematological malignancies in Latin America.





This report has been created through a literature review, observational site visits and validation of our findings with experts from the region

Key steps to arrive at report findings:



We reviewed over 100 publications to develop a view on good practices in the care and management of patients with haematological malignancy



Conduct literature review

Our approach:

1



We have reviewed over 100 academic and clinical publications in addition to high-quality grey literature from a number of reputable sources.

2



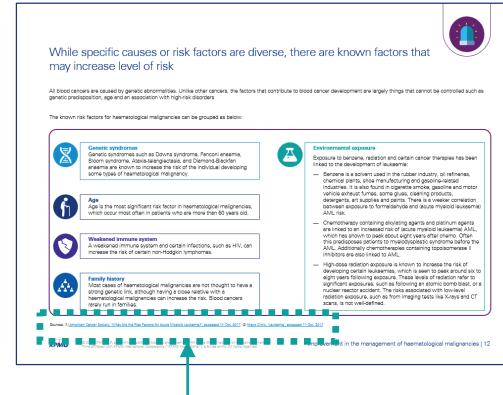
We have reviewed the major international guidelines for all indications in the scope of this report, including NCCN guidelines, ESMO guidelines and IWCLL guidelines.

3



We have consulted numerous publications by government and private institutions detailing healthcare good practices and future plans.

How we have shared our findings:



Throughout the report, we have referenced sources from our literature review on the relevant page. As we refer to the source throughout each slide, we have not added specific references to key points on the slide.

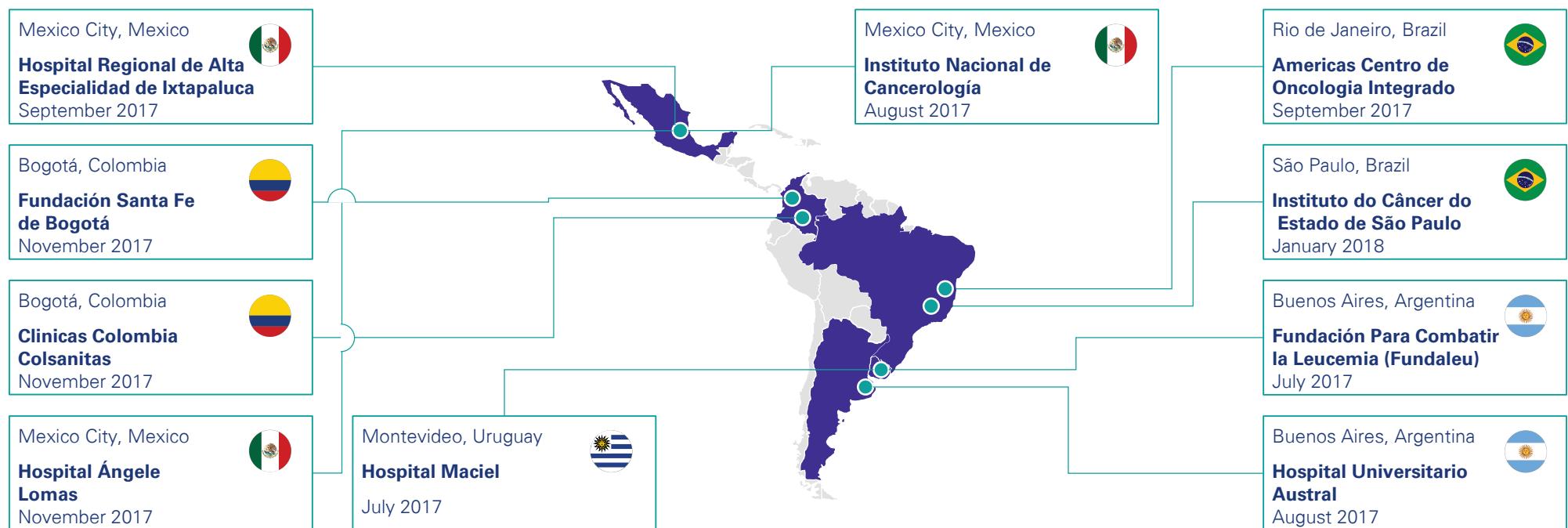
In the 'initiatives' section, we have referenced evidence to support the potential impact of each good practice initiative and have cited where this initiative has been observed during the visits.



We visited 10 leading centres, representing the majority of healthcare systems in the region, that are renown for high-quality patient care and management

Visit leading centres

- We engaged with patient advocacy groups throughout the project and they aided us in selection of ten key centres around Latin America.
- Centres were selected from across Latin America, and were representative of the majority of healthcare systems throughout the region.



We engaged with a wide variety of team members to understand how care is delivered in each of the selected centres



Visit leading centres

Through our visits we were able to engage with all key members who supported the patient journey, and discuss key aspects that enable the provision of high-quality care:



Who did we engage with?

Administrative staff

BMT team members

Cytogeneticist

Dentists

Haematologists

Haemo-oncologists

ICU care team

Imaging specialists

Infectologists

Integrative therapy practitioners

Internal medicine specialists

Nurses (including specialists)

Palliative care Specialists

Pathologists

Pharmacists

Psychiatrists

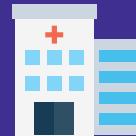
Psychologists

Radiologists

Social care workers



What did we observe?



Centre premises and facilities

We observed practice across a typical patient journey.



Processes

We observed the management of haematological malignancies from diagnosis and prognosis through to treatment including BMT and ICU services and across follow-up and palliative care.



Team interaction and governance

We enquired about the processes held within each centre regarding patient care. This included all MDT and training sessions held.



Educational materials and technological capabilities

We observed the educational materials provided by the hospital for the patients and the technological capabilities used in the management of their care.



Visit leading centres



What did we ask about?

We discussed key practices across the full haematological malignancy patient journey.



Centre background

Information about the centre and patient demographics.



Current practice

Challenges and activities across the patient pathway and highly valuable or unique actions the centres performed along the pathway.



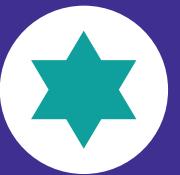
Patient centricity

How to ensure care is centred around the patient. Enabling them and their family to participate in the treatment and management of haematological malignancies across the care pathway.



Networks

Level of collaboration across departments as well as networks with other centres.



Benefit creation

Impact of good practice initiatives in haematological malignancy care on both the patients and the care delivery team.



We reviewed common factors underlying the good practice observed during site visits, and validated with experts and research



Synthesise findings & review with experts

Our approach:

Centre-specific findings:

- Through our visits to ten leading centres, we identified: key practices that underpin provision of high-quality care, and developed centre-specific reports detailing:
 - Key findings from the centre;
 - Case studies of specific initiatives.
- We shared these reports with each centre, to validate our findings for accuracy.

Common themes and initiatives of good practice:

- We synthesised our findings, identifying common themes of good practice and initiatives.
- We conducted additional literature reviews to validate our observed good practice initiatives, e.g. Internationally approved guidelines for evidence-based good practice care and management, peer-reviewed studies, publications by governments and private institutions detailing good practice.



Interactive workshop and review sessions:

- Through an interactive workshop comprising external experts (including chief haematologists from centres visited, regional experts and representatives of patient association groups), and individual review sessions, we worked together to validate and refine our findings.



We have outlined 5 overarching themes, 25 common initiatives and 70 case studies of good practice that enable leading centres to deliver high-quality care to patients



How we have shared our findings



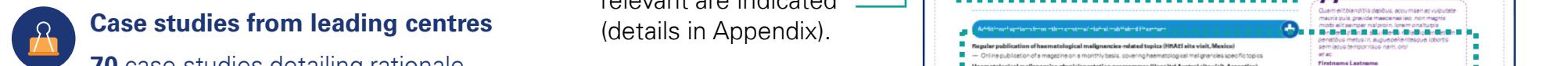
Themes encompassing good practice care

5 key themes of good practice haematological malignancy care and management, relevant across the full patient pathway.



Good practice initiatives

25 operational initiatives, collated from common practice across the leading centres visited, that can be replicated to achieve elements of good practice by other centres across the region.



Case studies from leading centres

70 case studies detailing rationale, features, resources and potential impact of specific good practice initiatives in place at the leading centres visited.

Standardising linkage to care

What is the challenge?
Limited awareness of haematological malignancies, and therefore a delay in recognition of warning signs is a common challenge throughout the Latin America region. This may be due in part to low level of awareness among primary/secondary care physicians to assess patient condition, e.g. disease progression or eligibility for BMT.

What is the good practice?

Which patient is it for?
All patients

Which staff members are involved?
Physicians in secondary or primary care settings

What is offered as part of this good practice?
Education and training programmes for managing physicians (community or secondary care based):

- Information sharing
- Skills training, e.g. recognition of relapse
- Processes for faster referrals

What are the objectives?

- Increase recognition of haematological malignancies
- Standardise patient care
- Standardise assessment of patient conditions
- Increase number and frequency of referrals to secondary care
- Standardise patient care

How was it achieved?

- Regular local workshops with community care physicians to standardise patient assessment and referral processes
- Identify local physicians and engage
- Hold regular sessions to discuss patient assessment, including BMT eligibility
- Agree and implement process for rapid referrals

What are the potential outcomes?

Clinical
Standardised methods of patient assessment and referral to specialist care

Patient experience
Faster diagnosis and access to care

4.9 Improvement in the management of haematological malignancies

Case studies from centres that are relevant are indicated (details in Appendix).

Evidence from literature to support each initiative is provided.

In 'Initiatives' section, each theme under which the initiative sits is clearly sign-posted.

The specific challenge the initiative is seeking to answer is outlined.

Selected case studies

BMT awareness programme - Instituto Nacional de Oncología, Mexico (see site visit report)
Fully sponsored programme for BMT specialists from around Mexico to standardise patient assessment and referrals

Physician training programmes - América Centro de Oncología Integrado, Brazil (see site visit report)
BMT awareness with local physicians to discuss referral pathways and patient assessment (e.g. symptoms, BMT eligibility)

Centralised screening and alarm system - Clínica Colombia Colombia, Colombia (see site visit report)
Central laboratory service screening samples nationally and expediting linkage to care when abnormalities are detected

Automated systems driven by computer - Hospital Austral, Chile (see site visit report)
Regular publication of haematological malignancy related topics (HRAST site visit, Mexico)

Haematological malignancy physician rotation programmes - Hospital Austral site visit, Argentina
Rotation programmes for young haematological malignancies from across Argentina to visit Austral and take part in lectures, ward rounds, learning methodologies, culture and mindset

Regular classroom training (Mayo clinic, USA)*
Multiple classroom courses on haematological malignancies covering processes across the treatment pathway, e.g. diagnosis, treatment, follow-up, and the role of the multidisciplinary team in haematological malignancies care and management and range from focused one-day sessions to comprehensive week-long courses

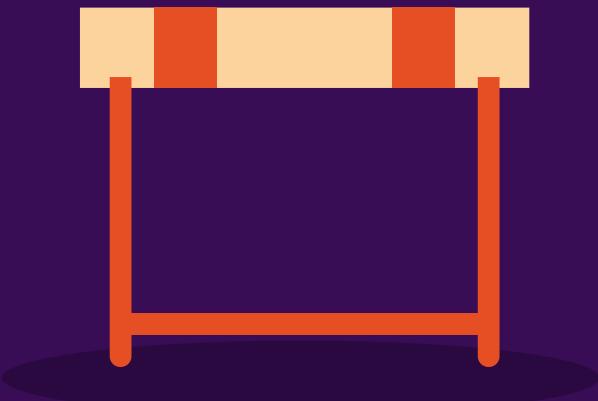
Supporting evidence from literature

1. Mayo Clinic, Mayo Clinic School of Continuous Professional Development, HSCourses

Improvement in the management of haematological malignancies | 50



5. Challenges in haematological malignancy care provision





We have outlined a selection of the many challenges that present barriers to the provision of good practice management and care of patients with haematological malignancies in Latin America.

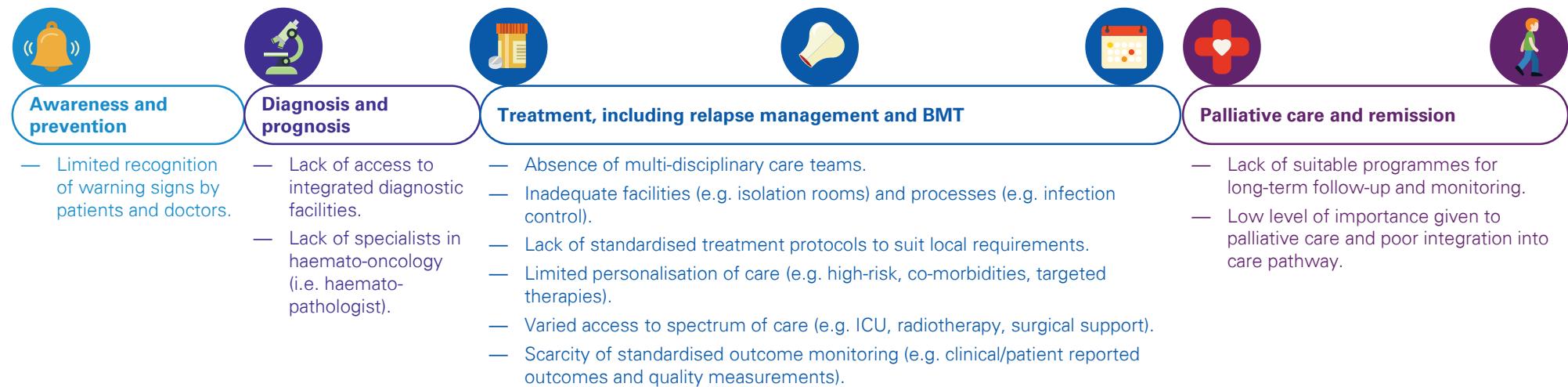
These exist at every stage of the patient journey through the treatment and care paradigm, with many presenting barriers to good practice at multiple different stages of the journey.

While many of these result from high-level issues, such as lack of funding, or national policy positions, many of them can be, and are being, addressed by a number of good practices developed by the leading centres in the region.



There are many challenges that impact the effective delivery of good haematological malignancy care in Latin America

Challenges specific to stages of the patient journey:



Challenges spanning the entire patient journey:

- Low level of access to care through haematological malignancies specialised tertiary centres.
- Limited patient and family engagement (communication, information, training) in disease management.
- Shortage of specialised expertise (e.g. haemato-oncology, haemato-pathology, clinical nurses).
- Restrictions in national public and private healthcare policies (e.g. coverage).
- Inefficiencies in linkage to care (e.g. transfer to community care, referrals from primary care).
- Shortage of funding for treatment centres (e.g. for infrastructure, facilities, technologies and staff).
- Lack of effective coordination between healthcare groups and patient support/advise groups.

6. Fundamental themes enabling good practice care provision



We identified five fundamental themes defining good practice initiatives, that enable centres to provide consistent, high-quality patient care



Enabling access to services

Ability to access services with ease improves patient convenience and quality of care; provided through location, number of services or speed to care.



Fostering a patient-centred care environment

A care environment that is built around the patient and carers will respond to the need to feel acknowledged and respected, and more engaged in treatment.



Creating an optimal care team model

Multi-disciplinary approach to care is essential for ensuring physical, mental and spiritual well-being of the patient and carers.



Providing high-quality medical management

Provision of rapid diagnostics, personalised treatments, novel therapeutics and specialised care to ensure highest possible patient and clinical outcomes.

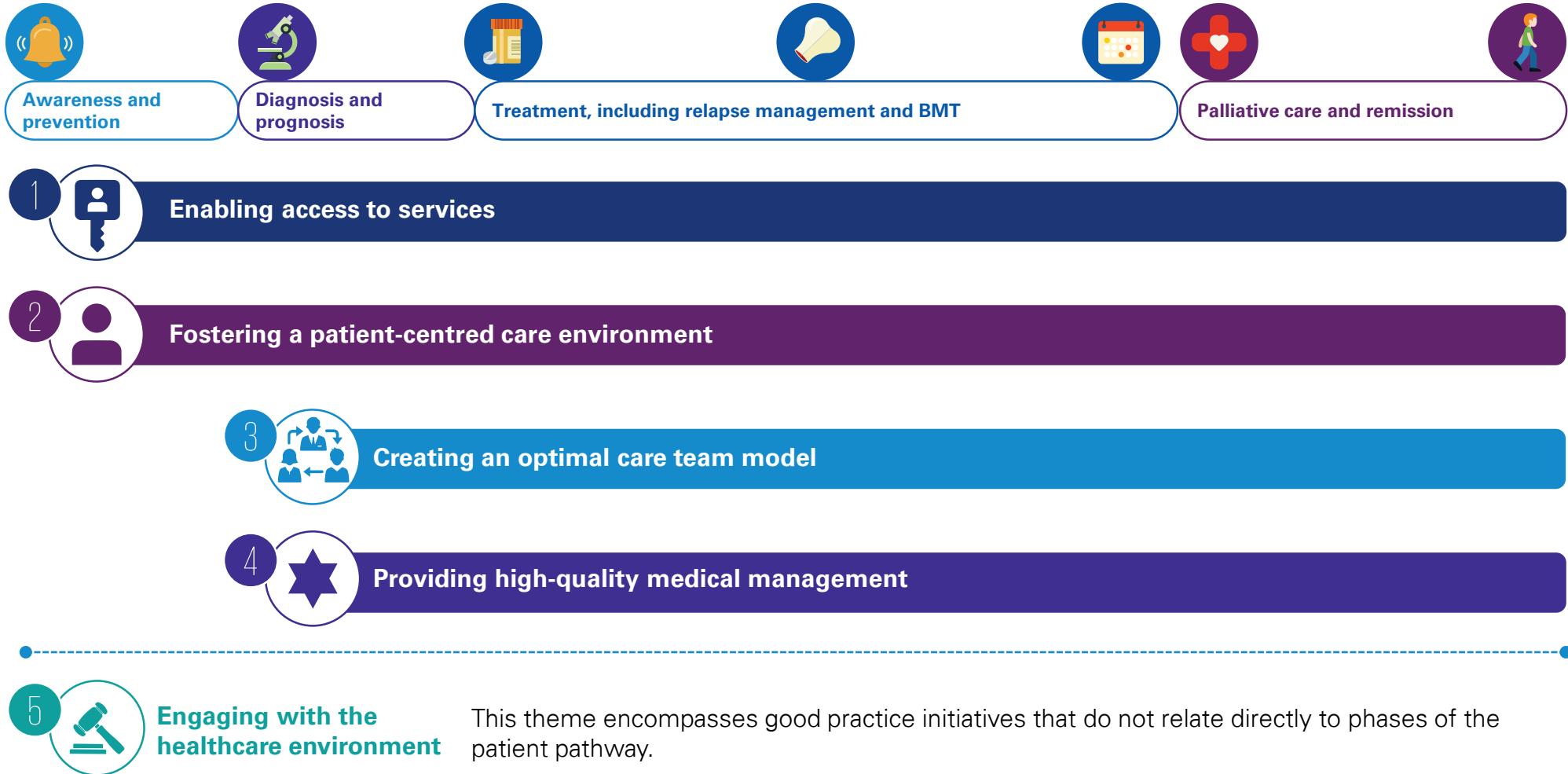


Engaging with the healthcare environment

Driving the improvement in standard of care across the country through active engagement in Payer, regulatory and policy issues.



These five themes of good practice care and management span the full journey for patients with haematological malignancies



Speed and convenience are essential factors enabling improvements in access to care and services



What do we mean?

Ability to access services rapidly and with ease improves patient convenience and quality of care; provided through location, number of services or speed to care.

Awareness and prevention

Diagnosis and prognosis

Treatment, including relapse management and BMT

Palliative care and remission

Key Requirements	Speed	Convenience
	<ul style="list-style-type: none">— Providing rapid services, including:<ul style="list-style-type: none">- Short waiting times to schedule first appointment;- Fast and accurate processing of diagnostic tests;- Quick referral to specialists/secondary care for follow-up/further treatment.*Improving speed and quality of referrals from the community.<ul style="list-style-type: none">- Training programmes to educate on criteria (e.g. symptoms including relapse, Bone marrow transplant eligibility).*Process for expediting urgent or acute cases.<ul style="list-style-type: none">- Developing a process of alarms for alerting specialists (e.g. haemato-pathologist) of samples requiring urgent investigation.	<ul style="list-style-type: none">— Ensuring timely initiation of treatment:<ul style="list-style-type: none">- Rapid referral from diagnostics to specialist care;- process for direct admittance from Emergency to wards (e.g. neutropenic sepsis patients).— Supporting access to treatment, where required:<ul style="list-style-type: none">- Team and procedure for processing insurance claims (public or private);- Engaging with social care for additional support.— Incorporation of palliative and supportive care to the patient journey:<ul style="list-style-type: none">- Provision of pain management options in a timely manner.*Provision of remote access to expert advice.<ul style="list-style-type: none">- Nurse or specialist run phone lines (24/7 availability);- Contact details of treating physician or care team.*Process for expediting urgent or acute cases.<ul style="list-style-type: none">- Establishment of fast-track framework to get urgent patients into care.

KEY: Requirements highlighted in **purple** and with a * denote 'flagship' practices (advanced good practice requirements). We consider these non-essential for provision of good practice, but aspects which greatly deliver additional value over a basic good practice model.



Fostering a patient-centred care relies on strong communication and provision of a suitable environment



What do we mean?

A care environment that is built around the patient and carers, which responds to the need to feel acknowledged and respected, and to feel more engaged in treatment

Awareness and prevention

Diagnosis and prognosis

Treatment, including relapse management and BMT

Palliative care and remission

Key Requirements	Communication	
Environment	<ul style="list-style-type: none">Ensuring regular, open and honest communication with patients and families:<ul style="list-style-type: none">Comprehensive discussion with patients and families before initiation of treatment plans (e.g. pre-BMT);Provision of supporting material (educational material) to ensure good understanding of condition, treatment and prognosis.Adapting method of communication to suit patient abilities/context:<ul style="list-style-type: none">Provision of information in a format that is accessible to patient and family (e.g. literacy/language/cultural barriers).	<p>*Provision of support to healthcare professionals for patient communication management (e.g. training programmes on communicating with patients including how to give bad news).</p> <ul style="list-style-type: none">Designing a safe and supportive care environment:<ul style="list-style-type: none">Availability of continuity of care (e.g. consistent primary treating physician);Minimising administrative and logistical burdens (e.g. administrative support teams, on-site pharmacies to remove burden of accessing medication).Ensuring patient emotional and psychological needs are addressed:<ul style="list-style-type: none">Ability to maintain contact with families during treatment such as Bone Marrow Transplants;Provision of supportive services (e.g. psychologists, nutritionist, rehabilitation specialists);Addressing potential cultural issues/considerations which present barriers to good care.Ensuring patients feel adequately supported and listened to throughout the journey:<ul style="list-style-type: none">Discussing all treatment options and enabling patient and family to work with healthcare professionals to decide best suited treatment plans.
Empowerment		<p>*Educating patients on how to communicate with physicians through special programmes designed to increase patient autonomy.</p>

KEY: Requirements highlighted in **purple** and with a * denote 'flagship' practices (advanced good practice requirements). We consider these non-essential for provision of good practice, but aspects which greatly deliver additional value over a basic good practice model.

Personalising care as much as possible can ensure greater patient satisfaction



What do we mean?

Multi-disciplinary approach to care is essential for ensuring physical, mental and spiritual wellbeing of the patient and carers

Awareness and prevention

Diagnosis and prognosis

Treatment, including relapse management and BMT

Palliative care and remission

Key Requirements	Availability
	Governance
	<ul style="list-style-type: none">— Availability (in-house or through specialist network) of diagnostics and prognostic laboratory team to support testing:<ul style="list-style-type: none">- Haemato-pathologists;- Full complement of technical specialists, including flow cytometrists, molecular biologists, cytogeneticists, immuno-histochemists etc.;- Psychologists;- Operational staff/specialist nurses to acquire samples as required.— Diagnostic team (e.g. haemato-pathologist) to be a regular member of the multi-disciplinary team engaged in patient care. <p>*Establishing an advanced MDT model to address the complete needs of patients and families members, potentially including.</p> <ul style="list-style-type: none">- Patient support group representative;- Integrative care practitioners (e.g. nutritionist, massage therapist, acupuncture specialist etc.);- Administrative support team (healthcare system navigators);- Service quality team.

KEY: Requirements highlighted in **purple** and with a * denote 'flagship' practices (advanced good practice requirements). We consider these non-essential for provision of good practice, but aspects which greatly deliver additional value over a basic good practice model



Provision of a personalised service and treatment regimen can ensure delivery of high quality medical management to patients

4

What do we mean?

Provision of rapid diagnostics, personalised treatments, novel therapeutics and specialised care to ensure highest possible patient and clinical outcomes

Awareness and prevention

Diagnosis and prognosis

Treatment, including relapse management and BMT

Palliative care and remission

Key Requirements	Tailored care	Personalised treatment	Palliative care and remission
	<ul style="list-style-type: none">Ensuring accurate diagnostics, particularly for suspected acute disease:<ul style="list-style-type: none">Availability of a haemato-pathologist (in house or through network);Access to full complement of diagnostic testing services.Developing tailored treatment plans to suit patient condition, e.g. patients with co-morbidities, pregnant patients, need for supportive care such as pain management.Developing process for engaging additional specialties in a timely manner, e.g. transfer to ICU, collaborating with internal medicine teams.Establishing strict protocols for patient safety, e.g. infection control, patient identification, patient risk assessment. <p>*Establishing specialised clinics for management of high risk patient groups, with multi-disciplinary team input and priority status for patients within the hospital (e.g. access to psychologists, social care workers).</p>	<ul style="list-style-type: none">Provision of access to best suited/novel treatment options:<ul style="list-style-type: none">Proactive participation in clinical trials;Engaging with Payers/other funding bodies for provision of medicine which may not be widely available/off-label.Inclusion of palliative and supportive care early in the patient journey, e.g. pain management.	

KEY: Requirements highlighted in **purple** and with a * denote 'flagship' practices (advanced good practice requirements). We consider these non-essential for provision of good practice, but aspects which greatly deliver additional value over a basic good practice model.

Proactive engagement through building knowledge, infrastructure and team can support in improving the healthcare landscape

5



What do we mean?

Driving the improvement in standard of care across the country through active engagement in Payer, regulatory and policy issues

Key Requirements	Specialist knowledge
Infrastructure and team	
	<ul style="list-style-type: none">— Building an environment in which specialist knowledge is built and expanded:<ul style="list-style-type: none">- Regular multi-disciplinary team meetings internally;- Continued staff training (e.g. attendance at conferences);- Facilitation of knowledge sharing (e.g. rotation programmes, external speaker events).— Ensuring protected time or resources to expand knowledge/improve patient management, e.g. guideline adaptation to suit local requirements, protected tie to undertake clinical research.— Setting in place external networks for greater collaboration, consensus building and/or lobbying:<ul style="list-style-type: none">- Developing consensus guidelines for patient management;- Developing 'best practice' guidelines for access to preferential reimbursement.— Availability of data management capabilities:<ul style="list-style-type: none">- Comprehensive patient databases to support analysis and research;- Dedicated resource/time for data analysis;- Process for data sharing across institutions/with national registries.— Provision of facilities for research/clinical research.— Dedicated teams for engaging with external bodies (e.g. Payers, registries such as blood banks or bone marrow unit):<ul style="list-style-type: none">- Trained teams Payer engagement, who manage all elements of patient administrative support.

KEY: Requirements highlighted in **purple** and with a * denote 'flagship' practices (advanced good practice requirements). We consider these non-essential for provision of good practice, but aspects which greatly deliver additional value over a basic good practice model.



7. Good practice initiatives in care and management



Underlying the five themes are 25 key initiatives, observed during our site visits to leading reference centres and validated by our panel of experts

Good practice initiatives described in this report:



Enabling access to services



Fostering a patient-centred care environment



Creating an optimal care team model



Providing high-quality medical management



Engaging with the healthcare environment

Good practice initiatives



Note: These identified good practice initiatives should not be viewed as isolated activities, as synergies that exist between them can be leveraged to generate a robust platform for a disease management model for haematological malignancies in Latin America (see page 123).



Enabling access
to haematological
malignancy
services





Standardising linkage to care



What is the challenge?

Limited awareness of haematological malignancies, and therefore a delay in recognition of warning signs presents a common challenge throughout the Latin America region. This may be due in part to low level of awareness among primary/secondary care physicians impacting the assessment of patients' conditions (e.g. disease progression or eligibility for bone marrow transplant). This limited awareness by both community physicians and the general public, along with the lack of knowledge regarding the correct referral pathway, and how to engage with it, is a potential cause for delayed linkage into care.

What is the initiative?



Which patient is it for?

- All patients.

Which staff members are involved?

- Physicians in secondary or primary care settings.

What is offered as part of this initiative?

- Education and training programmes for regional physicians (community or secondary care based):
 - Information sharing (e.g. eligibility for bone marrow transplant);
 - Skills training (e.g. recognition of relapse);
 - Processes for faster referral, and dissemination of information on how to initiate this process.
- A robust, standardised framework for referral which is present in the community and secondary care setting.

What have we observed?



What are the objectives?

- To increase recognition of haematological malignancies in the community at an early stage.
- To standardise assessment of patient conditions.
- To increase number and frequency of referrals to specialised/tertiary centres.

How was it achieved?

- Regular local workshops with community care physicians are held to standardise patient assessment and referral processes:
 - Identify local physicians and engage;
 - Hold regular sessions to discuss patient assessment, including BMT eligibility;
 - Agree and establish a process for rapid referrals.

- National level meetings on specific topics:
 - Bring together physicians from different settings of care to discuss specific topics, e.g. BMT;
 - Share insights and provide a forum for peer-learning;
 - An option is to work with industry or utilise government funding to cover expenses .
- Optional: Establishment of testing centres in the community with a standardised diagnostic criteria for referral and established routes for referral; testing could be performed centrally or in a de-centralised manner, providing the framework for diagnosis and the criteria for referral are standardised across the system.

What are the potential outcomes?



Clinical

- Standardised methods of patient assessment and referral to specialist care.
- Faster time to treatment resulting in improved treatment outcomes.



Patient experience

- Faster diagnosis and access to care.



Selected case studies



Bone marrow transplant (BMT) awareness programme – Instituto Nacional de Cancerología, Mexico (see site visit report)

Fully sponsored programme for BMT specialists from around Mexico to educate on standardised patient assessment and referrals.



Physician training programmes – Americas Centro de Oncología Integrado, Brazil (see site visit report)

Regular workshops with local physicians to discuss referral pathways and patient assessment criteria (e.g. symptoms, BMT eligibility).



Centralised screening and alarm system – Clinica Colombia Colsanitas, Colombia (see site visit report)

Centralised laboratory service screening samples nationally and expediting linkage to care when abnormalities are detected.



Patient regulation – ICESP, Brazil (see site visit report)

ICESP developed a form in order to ensure accurate diagnosis of haematological malignancy. This was adopted by the State Department of Health and has been rolled out across Sao Paulo to ensure that patients arrive at the hospital with a correct diagnosis.

Additional options from other centres/global published literature



Regular publication of haematological malignancy-related topics (Hospital Regional de Alta Especialidad de Ixtapalulca, Mexico)

— Online publication of a magazine on a monthly basis, covering haematological malignancies specific topics.

Haematological malignancies-physician rotation programmes (Hospital Universitario Austral, Argentina)

— Rotation programmes for young haematological malignancy trainees from across Argentina to visit Hospital Universitario Austral and take part in lectures and ward rounds, aimed at teaching learning methodologies, culture and mind-set.

Regular classroom training (Mayo clinic, USA)⁽¹⁾

— Multiple classroom courses on haematological malignancies (covering processes across the treatment pathway) are conducted. These are for all HCPs involved in haematological malignancy care and management and range from focused one-day sessions to comprehensive week long courses.

Supporting evidence from literature



1. [Mayo Clinic: Mayo Clinic School of Continuous Professional Development, HM Courses](#)



Providing accommodation for patients and their families



What is the challenge?

Haematological malignancies, whether acute or chronic, often require extensive and repeated periods of hospitalisation. Certain treatments (e.g. BMT) require standardised environmental conditions in which the patient lives, to maximise success of the procedure and minimise the risk of infections. Therefore patients, and their supporting family members, are often required to remain in, or local to the hospital for duration of treatment. As a consequence, patients and their families may experience significant expenses for accommodation near the hospital, and where they cannot afford this, lack of accommodation may present a barrier to treatment.

What is the initiative?



Which patient is it for?

- Patients with limited means of affording accommodation for themselves and their families for the duration of their treatment.

Which staff members are involved?

- Generally managed by social care/hospital navigators, with support from administrative staff.

What is offered as part of this initiative?

- Providing options for local residence for patients and their families:
 - Discounted/free accommodation for those who are unable to afford to stay in the hospital or nearby accommodation during the course of treatment;
 - Additional rooms are offered for family members.

What have we observed?



What are the objectives?

- To support patients with limited income to ensure they have the family support needed during their treatment.
- To improve patient and family convenience by remaining local to the treatment centre.

How was it achieved?

- Forming partnerships or networks with local hostels/housing/hotels:
 - Identification of, and building relationships with local accommodation options, e.g. hotels/housing from charities or religious groups;
 - Negotiating discounted rates to support patients with housing needs.

- Setting up hospital-funded housing:
 - Where possible, working with foundations/hospital funding bodies to acquire infrastructure and staff to provide the facilities required for patients and their families to stay in;
 - If funding available, this could be provided to patients free of charge.
- Implementing a system for means testing:
 - Working with patients to ensure those with high level of need are prioritised to access available/discounted/free accommodation. This is usually managed by administrative teams or social care workers.

What are the potential outcomes?



Clinical

- Improved clinical outcomes due to regular presence of patients, and in some cases better sanitary conditions.
- Better management of infections (e.g. post BMT, immunosuppressed).



Patient experience

- Improved convenience through ability of family to stay local.
- Better support due to family members being present.
- Ability to access care to those who may not otherwise be able.



Selected case studies



Haematological malignancy specialised social care support – Hospital Regional de Alta Especialidad de Ixtapaluca, Mexico (see site visit report)

Database of houses run by religious organisation or charities that can be accessed.



Porsaleu foundation – Hospital Maciel, Uruguay (see site visit report)

A separate foundation that collaborates with the hospital to provide free residence for patients and family members. Food is provided by the hospital.



Casa Hope – ICESP, Brazil (see site visit report)

A philanthropic foundation, independent to the hospital that provides residence for a patient and their family, as well as transport to and from hospital appointments.

Additional options from other centres/global published literature



Emergency access rooms (Fundaleu, Argentina)

— Set of rooms to house families of patients who fall critically ill and need accommodation immediately.

Discounted rooms (Fundaleu, Argentina)

— Patients and family member are able to stay in local accommodation for discounted rates negotiated by the Fundaleu foundation.

Long-term accommodation as well as transportation (Brigham and Women's Health, USA)⁽¹⁾

— Special lodgings are offered by some centres along with transportation to the hospital for patients and family at no/reduced fee.

Hospitality rooms (Wake Forest Baptist Health, USA)⁽²⁾

— These rooms are provided for family members as they wait whilst the patient undergoes treatment such as for radiation therapy. They are fully catered and run by volunteers.

Supporting evidence from literature



1. [Brigham and Women's Hospital: Special Arrangement Housing](#)
2. [Wake Forest Baptist Health: Cancer Patient Support Program, Hospitality Rooms](#)



Enabling treatment in the community



What is the challenge?

The management of haematological malignancies is predominantly conducted by tertiary centres at present, due to the need for specialised equipment (e.g. imaging), access to multi-disciplinary teams (e.g. haemato-oncology, nurses, haemato-pathology, clinical oncology) and access to specialist facilities (e.g. infusion centres, BMT units). Often these centres are located within large cities, requiring patients and families from rural locations to travel long distances. This results in added transportation and accommodation costs, as well as reduced convenience, often having a negative impact on patient and family/carer quality of life.

What is the initiative?



What have we observed?



Which patient is it for?

- Patients with limitations in accessing care, (e.g. living in rural areas), difficulties in travel to tertiary centres due to disability or lack of financial/transport means.

Which staff members are involved?

- Physicians, trained nurses and integrated care specialists (e.g. psychology) or supportive care (e.g. social work) as required.

What is offered as part of this initiative?

- Providing patients with care in the home.
- Supporting healthcare systems in the provinces.
- Providing training for staff (e.g. raising awareness, patient support, education, training of community members and HCPs).

What are the objectives?

- To increase number of patients treated.
- To improve patient convenience.
- To reduce costs for patients.

How was it achieved?

- Mobile delivery of care:
 - Identifying priority patients (e.g. immobility, immunosuppressed);
 - Setting in place processes for care delivery to remote locations (e.g. team, logistics such as transport);
 - Implementing a schedule of home visits (e.g. infusions, palliative care);
 - Maintaining regular contact and follow up to monitor outcomes.

- Training and support to community healthcare professionals:
 - Identification of specific needs (e.g. improving nurse specialists in the community, training GPs on the delivery of palliative care);
 - Creation of specific training programmes (e.g. specialists from reference centre visit provinces/invite regional HCPs to visit reference centre).

What are the potential outcomes?



Clinical

- Improved clinical outcomes due to regular provision of care/improved disease management.
- Reduced incidence of treatment lapse.



Patient experience

- Improved patient convenience.
- Reduced financial burden.



Selected case studies



Nurse training programme – Fundaleu, Argentina (see site visit report)

Delivery of training programmes to upskill nursing teams within regional hospitals.



Palliative care programme – Instituto Nacional de Cancerología, Mexico (see site visit report)

Delivery of palliative care services to patients in the home setting.



Haematomobile – Hospital Maciel, Uruguay (see site visit report)

Delivery of care in patient home setting by physician and trained nurses.



'Hello Nurse' programme – ICESP, Brazil (see site visit report)

A service offering contact to a nurse of patients and their family members 24 hours per day via a dedicated phone service.

Additional options from other centres/global published literature



Building networks of partners for care delivery (Americas Centro de Oncología Integrado, Brazil)

- Identifying a number of centres/hospitals and development of a set of agreed practices in delivery of care to ensure standardisation.

Patient and family education in treatment management (Instituto Nacional de Cancerología, Mexico)

- Engaging patient and family on managing certain aspects of care at home, (e.g. delivery of pain medication in the home setting).
- Providing material for regular documenting and monitoring of patient outcomes (e.g. monitoring notebooks).
- Creating a schedule for continuous and regular contact.

Collaborating with existing community centres (Memorial Sloan Kettering Cancer Alliance, USA)⁽¹⁾

- The centre has formed partnerships with local care providers in community centres. This benefits both the entities, the centre can increase its reach and the community centres receive access to high-level standardised care.

Supporting evidence from literature



1. [Memorial Sloan Kettering Cancer Center: Memorial Sloan Kettering Cancer Alliance](#)



Enabling provision of timely and convenient care



What is the challenge?

Management of haematological malignancies typically require a number of specialised facilities, including single dedicated wards (ideally single rooms) to minimise risk of infection in patients, isolation rooms for patients undergoing BMT/risk of high level of neutropenia, and outpatient facilities that are suitable for multiple interventions (e.g. long duration infusions). Access to facilities, either in house or through networks with other specialised centres, will support optimal patient outcomes.

What is the initiative?



What have we observed?



Which patient is it for?

- Patients requiring or undergoing any medical management in an inpatient or outpatient setting.

Which staff members are involved?

- Haematologists, transplant teams, clinical nurses.

What is offered as part of this initiative?

- Dedicated facilities and teams in house (e.g. designated wards or rooms).
- Access to facilities through network of specialised hospitals (e.g. BMT facilities).

What are the objectives?

- To provide optimal care through provision of purpose built facilities.

How was it achieved?

- Purpose-built infrastructure:
 - In-patient facilities that specifically meet the needs of haematological malignancy patients (e.g. isolation rooms for BMT with separated entrances that grant family access/method of communication with patient).
 - Outpatient facilities that provide maximum convenience to patients (e.g. open long hours to ensure long infusions are managed overnight).
- Networks with specialist hospitals for access to services.

- Developing relationships with specialist hospitals to provide rapid access to services.
- Setting in place procedures for continuity of care (e.g. through maintaining part of the same care team).

What are the potential outcomes?



Clinical

- Rapid access to treatment.
- Improved clinical outcomes for patients due to minimised infections and provision of best-suited care environment.



Patient experience

- Improved satisfaction.
- Better state of mind for patient and family.



Selected case studies



Network for BMT services – Americas Centro de Oncología Integrado, Brazil (see site visit report)

Works in collaboration with several highly-specialised BMT units for rapid transfer of patients who are eligible.



24/7 outpatient unit – Instituto Nacional de Cancerología, Mexico (see site visit report)

Outpatient unit that is open 24/7, enabling rapid access to patients post-diagnosis and maximising patient convenience.



Early discharge of bone marrow transplant patients – ICESP, Brazil (see site visit report)

An programme that helps enable patients to return to their homes sooner, in order to reduce susceptibility to hospital infection and helping to reduce both the patient, financial and capacity burden conferred by long periods of hospitalisation.

Additional options from other centres/global published literature



Designated area with a separate entrance outpatient unit (National Institute of Health and Care Excellence (NICE) guidelines)⁽¹⁾

- Guidelines suggest the development of a designated area, ideally with a separate entrance, that provides suitable protection to haematological malignancy patients from potential infections. Additionally these should provide facilities for long duration infusions, multiple medications and/or blood component transfusions.

Ambulatory care (National Institute of Health and Care Excellence (NICE) guidelines)⁽¹⁾

- Guidelines suggest the provision of ambulatory care for specific patients (e.g. those in remission or at increased risk).

Dedicated radiation oncology department (Cleveland Clinic, USA)⁽²⁾

- Provision of separate radiation department with personalised treatment plans for patients delivering radiation with high precision, reducing treatment time.

Partnership to deliver radiotherapy (University of Cincinnati Medical Centre and Cincinnati Children's Hospital Medical Center, USA)⁽³⁾

- These centres have partnered to provide radiation therapy to cancer patients with very high precision utilising UCMC Proton Therapy Center.

Supporting evidence from literature



1. [Facilities and staffing: Haematological cancers: improving outcomes. NICE guidelines, published May 2016](#)
2. [Cleveland Clinic: Radiation Oncology](#)
3. [University of Cincinnati Cancer institute, Proton Therapy at University of Cincinnati Medical Center, 2016](#)



Fostering a patient-centred care environment





What is the challenge?

A common theme to emerge is the need for improved patient and family education, on diagnosis, treatment options and the impact these will have on physical and mental well-being. This is exacerbated by the often highly complex nature of haematological malignancies, and the possible need for repeated testing for diagnosis/repeated treatment interventions (e.g. high dose chemotherapy followed by BMT). Clear and honest communication of information in unambiguous and patient-friendly formats is needed to ensure patients and their families are able to make informed choices about their care.

What is the initiative?



What have we observed?



Which patient is it for?

- All patients and their families/carers.

Which staff members are involved?

- Treating haematologists, nurses, social care workers and administrative support staff.

What is offered as part of this initiative?

- Structured programmes that engage patients regularly; these may consist of:
 - One-on-one sessions with patient and healthcare/social care professional;
 - Telephone lines for rapid information;
 - Multi-channel communication (e.g. videos, magazines, brochures).

What are the objectives?

- To better inform patients and families on the condition and its possible consequences/impact.
- To better prepare patients and families to deal with haematological malignancy management and timelines associated with the disease.
- To free up time of physicians to focus on medical management.

How was it achieved?

- A number of structured programmes are put in place, together providing continuous engagement to improve patient and family understanding:
 - Nurse specialist/social care worker hosts one-on-one meetings with patient upon admission; and at regular points through treatment period;
 - Availability of a nurse specialist on the phone for convenient information dissemination. Mobile

numbers of a nurse/physician may also be shared with patients for emergencies;

- Formal training programmes to educate patient/family on specific aspects of care (e.g. wound or catheter care, palliative care);
- Regular provision of educational materials (e.g. brochures or videos) to supplement face to face education.
- Creating up to date patient-focused educational materials that are relevant and fit for purpose:
 - Identification of major educational topics and best modes of communication (e.g. audio or graphics to overcome issues with illiteracy);
 - Creating collateral in house (e.g. videos, brochures).

What are the potential outcomes?



Clinical

- Better preparation for timelines and impact of therapy, which may be very intensive.



Patient experience

- Better satisfaction due to greater understanding of impact.
- Better preparation of family and patient for realities of treatment and timelines associated with their disease.



Selected case studies



Patient and family education programmes – Hospital Regional de Alta Especialidad de Ixtapaluca, Mexico (see site visit report)

Videos created in house, discussing each haematological malignancy indication and its treatment as well as patient safety (e.g. handwashing), which is available on TVs in common areas and patient rooms.



Patient and family training in palliative care – Instituto Nacional de Cancerología, Mexico (see site visit report)

Patient and family invited to INCan where they are provided specific training on wound/pain management and monitoring of patient condition (e.g. symptom tracking).



Meet the experts' breakfasts – Hospital Ángele Lomas, Mexico (see site visit report)

Breakfasts are held by physicians within the department to provide a platform for the public to learn and question about the disease.



Group setting support provision - ICESP, Brazil (see site visit report)

Sessions are held for patients and their families to openly discuss the major issues and concerns they have regarding their disease and treatment regimen.

Additional options from other centres/global published literature



Patient mutual support groups (Leukemia & Lymphoma Society Support Group-Holy Cross Hospital, USA)⁽¹⁾

- Haematological malignancy patients, family members and care providers connect on monthly basis to provide a forum for support and an opportunity to share their experiences and discuss any concerns they may be having.

Cancer education programme service (Mayo Clinic, USA)⁽²⁾

- Cancer education centre is freely accessible online, providing all information on most of the cancers. It serves patients by providing answers to any queries, through both telephone and email.

Supporting evidence from literature



1. [Holy Cross Hospital: Leukemia & Lymphoma Society Support Group](#)
2. [Mayo Clinic: Patient and Visitor Guide Cancer Education, Cancer Education Program Services](#)



What is the challenge?

Ensuring patients understand and feel comfortable with their physicians is essential for empowering them to play an active role in their care. Creation of a safe and secure environment where the patient feels they are under the care of knowledgeable physicians, who fully understand and know how to treat their condition is critical for both the patient and the family to be satisfied with their care. Trust can only be formed through creation of deep relationships between the physicians the patients and their families, and this requires time and effort.

What is the initiative?



Which patient is it for?

- All patients.

Which staff members are involved?

- All stakeholders involved in the care and management of patients must play a role in gaining their trust. This involves the physicians and nurses during the course of treatment, in addition to administrative and auxiliary staff who are charged with helping the patient navigate and orient themselves within the healthcare system.

What is offered as part of this initiative?

- Patient feedback collection:
 - Verbal;
 - Completion of forms.
- Formation of trust through informal contracts:
 - Education;
 - Communication forums.

What are the potential outcomes?



Clinical

- Better engagement from patients in their own care.
- Better understanding and less resistance to treatments.

What have we observed?



What are the objectives?

- To ensure patient buy-in and greater understanding of their treatment management as it is essential in ensuring complete participation in treatment plan and directly correlates with improved health outcomes.
- To ensure patient satisfaction and comfort while in treatment.
- To better prepare patients and families to deal with haematological malignancy management and timelines.

How was it achieved?

- Collection of patient feedback on their treatment and time in care, and evidence of direct tangible actions addressing patient concerns, demonstrate that patient's voices are listened to. This feedback can be collected in a number of methods:
 - Patient feedback collection forms, issued throughout a patients stay and at the point of discharge:

- Review meetings to discuss the outputs are held, occasionally with patients present.
- Weekly forums between patients and hospital staff to discuss the care received and how to improve it;
- Family/carer feedback collection.
- Formation of strong trusting relationships with patients and their families:
 - Training programmes to ensure correct approach to ensure effective communication with the patient;
 - Education programmes;
 - Collateral support - information notices/booklets.
- Ensuring the patients are aware of their rights and able to make fully informed decisions with regard to their treatment at all times. This can be achieved through:
 - Use of hospital notice boards outlining patient rights;
 - Extended appointment times where patients are able to express their concerns and discuss their condition fully with a medical professional.



Patient experience



- Better satisfaction and greater understanding of care/treatment regimen due to trusting physicians.
- Increased comfort and assurance throughout treatment processes – patient empowerment.



Selected case studies



Informal contracts – Hospital Universitario Austral, Argentina (see site visit report)

The concept of an informal contract is developed and supported through training to enhance communication between the patient and physicians as well as support through educational materials. Physicians and patients agree to work together, accounting for the needs of the other party, to produce the best health outcomes.



Patient feedback collection – Hospital Maciel, Uruguay (see site visit report)

Feedback is collected from both inpatients and outpatients at every discharge, and twice per year. This is supported by reviews with all physicians involved in care and open discussion forums.



Patient engagement, ICESP, Brazil (see site visit report)

A programme is run to induct and educate patients around the haematological malignancy treatment programme within the hospital, ensuring they adequately understand and are fully engaged in their treatment.

Additional options from other centres/global published literature



Triangulation of patient and family feedback through multiple platforms (NHS University Hospital of Leicester, UK)⁽¹⁾

— The centre gathers patient's and family member's feedback through various mediums. These include a 'Friend and Family Test', survey for all discharged patients, NHS Choices/Patient opinion online surveys, 'Message to a Matron' cards for complaints. These are reviewed and categorised every three months and subsequently attended to.

Patients as Partners approach is suggestive of improved trust⁽²⁾

— Faculty of Medicine of the University of Montreal conducted a study involving patients as partners or engaging them in the key decisions related to their healthcare. It positively impacts all HCPs' relationships with the patients as well as enabling the patients to feel empowered and proactive in their care.

Supporting evidence from literature



1. [NHS University Hospital of Leicester, Triangulation of patient feedback](#)
2. [Marie-Pascale Pomey et al., Patients as Partners: A Qualitative Study of Patients' Engagement in Their Health Care, Apr 2015](#)



What is the challenge?

Provision of palliative and supportive care is key to management of patients with haematological malignancies. The aggressive progression of certain haematological malignancies, together with the impact of intense treatment, often mean symptom control (e.g. pain) and life-sustaining interventions (e.g. blood product support) becomes essential to enable patients to maintain a good quality of life. Additionally a significant proportion of patients will progress to require palliative or end-of-life care. Close integration of palliative and supportive care specialists into the patient management process is essential for successful coordination of these services with those treating the haematological malignancy. Unfortunately, there are limitations in the recognition of the importance of palliative and supportive care services, and the availability of specialists and facilities for their integrated provision.

What is the initiative?



What have we observed?



Which patient is it for?

- Patients who require supportive care to supplement treatment, or who will or have already transitioned into palliative management.

Which staff members are involved?

- Palliative care specialist, pain management specialists, specialist nurses (support from the MDT).

What is offered as part of this initiative?

- Dedicated in-patient palliative and supportive care unit with specialised team:
 - Personalised management of patients with supportive needs within haematology wards.
- Palliative care in the community (e.g. home setting):
 - This could include training for family to monitor patient and deliver aspects of care.

What are the potential outcomes?



Clinical

- Improved management of treatment or disease symptoms (e.g. pain) and patient quality of life towards end of life.



Patient experience

- Greater feeling of support for both patient and family;
- Time to adjust to transition and progression of disease;
- Better QoL due to closer monitoring of needs and regular support.



Selected case studies



Comprehensive palliative care – Hospital Ángeles Lomas, Mexico (see site visit report)

Palliative care programme (including pain management) delivered to patients at home or in the hospital. This programme is often funded out of pocket by patients.



Community based palliative care – Hospital Regional de Alta Especialidad de Ixtapaluca, Mexico (see site visit report)

Palliative care provided within the home setting, for patients who prefer to remain at home. With training offered to community care GPs to enable them to better support patients.



Care team – Hospital Maciel, Uruguay (see site visit report)

Palliative care and psychological emotional support, working very closely with the haematological malignancy team for integrated care.



We are trying to move away from traditional way of providing palliative care and start engaging much earlier in treatment journey and working hand in hand with the haemato-oncology team.

Palliative care specialist, HRAEI, Mexico

Additional options from other centres/global published literature



Ambulatory care (National Institute for Health and Care Excellence (NICE) guidelines)⁽¹⁾

— Provision of key elements of care (e.g. blood transfusions) in the home or community setting.

Interdisciplinary team of palliative specialists (Mayo Clinic, USA)⁽²⁾

— The team collaborates with all the specialists involved in the treatment of the patient as well as with family members in order to help support these individuals and improve the quality of life of the patient.

Early involvement of Palliative care (American Society of Clinical Oncology (ASCO) guidelines)⁽³⁾

— Latest guidelines by ASCO suggest involvement of palliative care in cancer treatment within eight weeks for advanced cases. The guidelines suggest the essential components for care to include building rapport and relationship with patients and family, assessment and support of coping needs, and coordination with other care providers.

Supporting evidence from literature



1. [Palliative care: Haematological cancers: improving outcomes. NICE guidelines, published May 2016](#)
2. [Mayo Clinic: Palliative care](#)
3. [The ASCO Post: ASCO Clinical Practice Guideline Update: Integration of Palliative Care Into Standard Oncology Care, Apr 10, 2017](#)



What is the challenge?

Haematological malignancies are chronic conditions and relapses are common. There are limitations in patient and community physician ability to adequately monitor ongoing patient symptoms associated with their haematological malignancy. Patients are at risk of being lost from the system at a number of points in the patient pathway. In some haematological malignancies, patients are not treated immediately, but enter a 'watch and wait' phase, only receiving treatment when the disease progresses to a specific point. Following treatment, patients can go into remission for long periods of time, making monitoring for relapse difficult. Processes of defined and regular contact are important to ensure regular monitoring and continuity of care, and are essential to ensure optimal patient outcomes.

What is the initiative?



What have we observed?



Which patient is it for?

- All patients, especially those who are considered at high-risk of being lost from the system, or high risk of complications or relapse (e.g. post-BMT).

Which staff members are involved?

- All staff required in treatment of the patient across integrated specialities.

What is offered as part of this initiative?

- Regular, defined contact between the patient and medical professional as required by the patient's condition/disease state (e.g. weekly/bi-weekly follow-up post discharge).
- Quick admittance of previous patients who have relapsed.

What are the potential outcomes?



Clinical

- Improved clinical outcomes as:
 - Patients not eligible for treatment are kept in the system and transferred into treatment as soon as their disease progresses;
 - Relapses are spotted earlier, therefore treatment can be initiated in a more timely manner.



Patient experience

- Increased satisfaction due to feeling secure that their condition is being adequately monitored.
- Greater convenience for patients as they can manage time.



Selected case studies



Day clinic for outpatients – Americas Centro de Oncologia Integrado, Brazil (see site visit report)

A drop in day clinic for outpatients with access to dental, dermatology and psychology on top of haemato-oncology services.



'Hello Nurse' programme – ICESP, Brazil (see site visit report)

A service offering contact to a nurse of patients and their family members 24 hours per day via a dedicated phone service.



Oncology route programme – Clinica Colombia Colsanitas, Colombia (see site visit report)

Programme to standardise and optimise the processes delivering linkage to care and monitoring and follow-up after treatment.

Additional options from other centres/global published literature



Management of toxicities in immunotherapy (European Society for Medical Oncology (ESMO) guidelines)⁽¹⁾

— There are high chances of toxicity in treatment and follow-up of haematological malignancies such as gastrointestinal toxicity, renal toxicity etc. Guidelines suggest that effective monitoring and management of these should be available to patients throughout care.

Long-term follow-up guidelines for children's oncology⁽²⁾

— Guidelines for long term management of care for children, adolescent and young adult survivors of cancer indicating all possible associated risks and the requirements of periodic evaluation.

Supporting evidence from literature



1. [C. Robert et al., Management of toxicities from immunotherapy: ESMO Clinical Practice Guidelines for diagnosis, treatment and follow-up, Jul 2017](#)
2. [Long Term Follow up Guidelines for Survivors of Childhood, Adolescent and Young Adult Cancers, Oct 2013](#)



Working closely with patient groups



What is the challenge?

Across the region, the patient journey for haematological malignancies is complex and significantly fragmented. There are numerous points where the patient (or their family) are required to make the linkage between stages of care, and these represent potential stages at which the patient can become lost from the system. This is compounded by the fact that the healthcare professionals and stakeholders involved in delivering care to patients do not have sufficient time to provide detailed guidelines and education to empower patients to self-manage or handle transitions between different healthcare settings. Independent patient groups or support bodies are present in the majority of countries in Latin America, and could be effectively engaged to provide this support and orientation within the healthcare system, in addition to providing additional support and education to the patient and their family regarding the disease and its management. Unfortunately integration between these groups, and primary, secondary and higher level treatment centres and hospitals is limited.

What is the initiative?



Which patient is it for?

- This is relevant to all patients and their families at all stages of the patient journey.

Which staff members are involved?

- The care team in all levels of care is required to coordinate and educate representatives of key patient advice groups.

What is offered as part of this initiative?

- A point of contact outside of the hospital/healthcare system which the patient and their family can go to for further information.
- Help to navigate the healthcare system as patients progress through the patient journey.

What are the potential outcomes?



Clinical

- Fewer patients would be lost from the system, ensuring more patients are treated.

What are the details of this initiative?

What are the objectives?

- To ensure that patients and their families are able to get sufficient information and support to understand their disease and treatment plan.
- To have the patient sufficiently empowered, such that they can play an active role in hospital protocol development, clinical trial sourcing and entry etc.
- To help patients navigate the different levels of the healthcare system effectively, and prevent patients being lost from the system.

How would it be achieved?

- Higher level treatment centre and hospitals are required to liaise directly with patient groups. This will serve to:

- Ensure that patient group representatives understand the referral pathways, key contacts and all required processes;
- Allow the hospitals to share all relevant educational materials with patient group representatives.
- Patient groups would be actively integrated into the patient journey by primary and secondary care centres, allowing them to support and guide the patient and their family through the process and to provide sufficient education to allow self-management of relevant aspects of the disease.



Patient experience

- Patients and their families would be more familiar with the referral process.
- They would be more knowledgeable about their disease, and better placed to be more involved in the decision making and self-management where relevant.



Selected case studies



Porsaleu foundation – Hospital Maciel, Uruguay (see site visit report)

Hospital Maciel works with a patient support organisation, to collectively provide patient accommodation in a convenient location for those who require it. This is also used as a platform to provide education to patients and their families.



Patient advocacy/advice groups engaged during the course of investigations to support this report, and comprising key members of our expert advisory committee, have identified this as a key aspect that could support the patient journey, however which is significantly underused.

Additional options from other centres/global published literature



Patient groups and other voluntary sector bodies viewed as strategic partners by healthcare bodies ⁽¹⁾

- NHS England published a document outlining a model for future patient care, centred around empowering patients and communities. In this document, voluntary sector bodies were positioned as key partners to support this direction, along with the traditional healthcare partners and bodies such as the HTA body NICE.

Patient groups support and positive effect on improving outcomes in breast cancer patients in Latin America ⁽²⁾

- The Karolinska Institute published a paper measuring breast cancer outcomes in Latin America, advocating the importance of the role of patient groups in supplementing the gaps in healthcare systems to support patients across their treatment journey. These include the provision of information services and education for the patients and their family regarding treatment, symptoms and concerns etc. This paper was supported by key healthcare partners such as WHO and American Cancer Society.

Supporting evidence from literature



1. <https://www.england.nhs.uk/wp-content/uploads/2015/12/vanguards-support-directory.pdf>
2. [N. Justo et al. A review of breast cancer outcomes in Latin America](#)



Creating an optimal care delivery team





Working in a multidisciplinary environment



What is the challenge?

Effective management of haematological malignancies require a team of specialists, who are able to assess a patient's condition and develop tailored treatment plans. This is a requirement for all patients, however, becomes more important for new patients (including newly relapsed) and for those with co-morbidities. Bringing together input from haematology, internal medicine, haematopathology, nursing, psychology, pharmacy, clinical oncology, radiotherapy and other professionals can provide an integrated care plan that ultimately improves clinical outcomes.

What is the initiative?



Which patient is it for?

- All patients, particularly newly diagnosed/relapsed patients or those with complex conditions.

Which staff members are involved?

- All core team: haematologists, haematopathologists, nurses, transplant team members; with clinical oncologists, radiotherapists, palliative care specialists, radiotherapists, pharmacists, psychologists, dieticians, dentists and allied professionals (e.g. social care, rehabilitation specialists).

What is offered as part of this initiative?

- Formal MDTs with structured, regular meetings.
- Structured inter-disciplinary patient management activities (e.g. ward rounds).
- Ad-hoc MDT consultations as requested.

What have we observed?



What are the objectives?

- To provide fully integrated patient care.
- To implement regular collaboration and learning opportunities.

How was it achieved?

- Formal MDT meetings:
 - Regular structured MDT meetings (e.g. weekly):
 - An advanced option is separate MDTs for different haematological malignancy indications (e.g. CML/ALL or for care settings, outpatients).
 - Dedicated staff member (administrative) to organise and disseminate minutes of meeting.
 - Relevant patients discussed, and care plans agreed based on input from all specialists in attendance.

— Interdisciplinary patient management:

- Continued collaboration on a daily basis for patient management (e.g. haematology and internal medicine conduct ward rounds together);
- Any treatment modifications are made with immediate consultations between the two teams.

What are the potential outcomes?



Clinical

- Better case management and therefore better treatment outcomes.
- Novel learnings and treatments shared between team.
- Fostering better team environment.



Patient experience

- Better trust in medical team through receiving integrated care.
- Better feeling of safety.



Selected case studies



Weekly MDT meetings – Fundaleu, Argentina (see site visit report)

Number of MDT meetings per week (e.g. indication specific, academic, outpatient) to assess patients and develop integrated treatment plans.



Interdisciplinary patient management – Hospital Universitario Austral, Argentina (see site visit report)

Ward rounds conducted on a daily basis by haematology and internal medicine, with patients assessed and treatment plans updated in collaboration.



MDT approach to patient care – Hospital Regional de Alta Especialidad de Ixtapaluca, Mexico (see site visit report)

MDT team that meets on a weekly basis to discuss new patients, with emergency/ad hoc sessions conducted when needed (e.g. high-risk patient admitted).



Haemato-oncology and internal medicine working together like this is very unusual as its not often done so closely together in other hospitals.

Head, Internal Medicine, Hospital Austral, Argentina

Additional options from other centres/global published literature



Establishing a comprehensive core and extended MDT (National Institute for Health and Care Excellence (NICE) guidelines)⁽¹⁾

- Guidelines suggest establishing MDTs for care of every haematological malignancy patient, with clear processes for meetings, as well as listing follow-up actions and how to effectively measure their implementation. The MDTs should consist of core members involved in the delivery of haematological malignancy care and management; with additional ad-hoc experts (e.g. dentists and infectologists) to be invited to take part as needed.

Supporting evidence from literature



1. [Multidisciplinary teams: Haematological cancers: improving outcomes. NICE guidelines, published May 2016](#)



Establishing dedicated administration support teams



What is the challenge?

Management of haematological malignancies requires co-ordination between multiple external bodies (e.g. national or international donor banks for bone marrow, Payers for approval of certain treatments, social services). This creates a significant administrative burden, which may need to be handled by physicians or patients. Dedicated individuals or teams that manage these tasks can free up patient/family and physician time and also ensure needs of patients and carers are identified and met.

What is the initiative?



Which patient is it for?

- Patients who need to engage with external bodies (e.g. social services, healthcare providers etc.).

Which staff members are involved?

- Administrative support teams and social care workers.
 - May require new staff to be hired to form a dedicated team.

What is offered as part of this initiative?

- Specialised social care workers who manage haematological malignancy patients.
- Dedicated teams who manage all administrative aspects of patient and physician needs.

What have we observed?



What are the objectives?

- To provide patients with access to services required, e.g. social care.
- To reduce administrative burden on patients and physicians.

How was it achieved?

- Creating specialised social care workers for haematological malignancy patients:
 - Engage with patients on first arrival at hospital, and start to build relationship;
 - Structured process for data collection (e.g. income, family make up) and assessment of patient financial status for payment and additional social care support (e.g. tiered assessments);

- Regular and continuous contact with patients to understand their needs, and provide support where needed (e.g. housing needs, financial or mental health support).

- Implementing dedicated administrative support teams:
 - Provide training to team members to ensure good understanding and alignment with haematological malignancy care delivery team values;
 - Process for engaging with administrative team on a regular basis (e.g. weekly meetings);
 - Guidelines on administrative tasks undertaken (e.g. liaising with donor banks, engaging local social services, providing logistic and navigation support to patients).

What are the potential outcomes?



Clinical

- Increased patient treatment adherence to regimens due to better support for patient and family.
- Faster access to treatments due to expedited administrative processes.



Patient experience

- Improved trust in the hospital care delivery team.
- Feeling of being well supported, with needs of patient and family given priority.



Selected case studies



Pre-transplant support team – Hospital Universitario Austral, Argentina (see site visit report)

A dedicated two person team who are members of the haematological malignancy care delivery team managing all aspects of transplant-related administrative work (e.g. liaising with payers/donor banks, working with social care) and providing one-on-one support to patients (e.g. hospital navigation).



Haematological malignancy specialised social care support – Hospital Regional de Alta Especialidad de Ixtapaluca, Mexico (see site visit report)

Comprehensive support for patient from first arrival at hospital to discharge, providing assessment of income, and access to social care services through an individual dedicated haematological malignancies service.



We want the patient to forget completely about the administrative side of things, and leave all the bureaucracy to us.

**Member of the pre-transplant support team,
Hospital Austral, Argentina**

Additional options from other centres/global published literature



Role of oncology nurses in chemotherapy⁽¹⁾

— Specialist nurses play a key role in delivering chemotherapy and can effectively improve patient care with increased awareness and timely assessment of any side effects/symptoms.

Hospitals can collaborate with specific support worker providing organisations (Macmillan, UK)^(2, 3)

— One-to-one support workers provide emotional as well as practical support to the patients and their family. They help to coordinate with physicians and help instigate effective care both within and external to the hospital. This has proven to positively impact the patients and the sector they work within.

— Some of the specific expectations and requirements from support workers are: ensure coordination among everything by becoming sing point of access; and posses basic IT and organisational skills.

Supporting evidence from literature



1. [Helen Roe and Elaine Lennan, Role of nurses in the assessment and management of chemotherapy-related side effects in cancer patients, Feb 2014](#)
2. [Macmillan, Support worker, Impact briefs, 2015](#)
3. [Macmillan, Indicative role specification for a Macmillan cancer support worker – care coordination, Aug 2011](#)



Expanding the role of pharmacists



What is the challenge?

Patients suffering with haematological malignancies require long term, complex treatment regimens and can often suffer from co-morbidities. Provision of effective medication (avoidance of polypharmacy, inadequate posology), minimising errors and close monitoring of adverse events are critical to ensuring optimal patient outcomes are achieved. Pharmacists are well placed to support the full care team in this respect, however are often afforded limited presence in the patients journey, impacting their ability to play a fully active role.

What is the initiative?



Which patient is it for?

- All patients, particularly those with complex medical histories, co-morbidities or complex treatment regimens requiring robust knowledge of medicinal properties.

Which staff members are involved?

- Pharmacist and administrative staff.

What is offered as part of this initiative?

- Pharmaceutical services.
- Risk management:
 - Drug monitoring and drug interactions;
 - Pharmacovigilance.

What have we observed?



What are the objectives?

- To provide effective mediation to the patient, and reduced wastage resulting from incorrect or inefficient prescriptions.
- To improve patient safety – close monitoring and minimising errors.
- To integrate the pharmacy team into the medical management process.

How was it achieved?

- Triple verification of medicines in the chain of dispatch ensures that the correct dose of the correct medication for each patient is received and that quality is optimal.
- Pharmacists perform validation of all prescriptions by treating physicians. In this process pharmacists consider all relevant aspects such as drug-drug

interactions, patients comorbidities etc. to ensure the prescription is suitable. This ensures that patient safety is upheld and that wastage of medication from incorrect prescriptions does not occur.

- Close patient relationships are established as the pharmacist is a core member of the multidisciplinary team, and is consequently able to inform treatment decisions based on individual knowledge of patients.
- The pharmacists are additionally responsible for coordinating drug monitoring and reporting of adverse events/pharmacovigilance.

What are the potential outcomes?



Clinical

- Better treatment outcomes due to patients being correctly medicated in a timely manner.



Patient experience

- Better satisfaction receiving correct medication.
- Continual support and closer relationships with physicians.



Selected case studies



CISFA – Hospital Regional de Alta Especialidad de Ixtapaluca, Mexico (see site visit report)

24/7 availability of pharmaceutical services, with telephone availability for patient queries, managing ~6,000 prescriptions per week.

Additional options from other centres/global published literature



Role of oncology pharmacists⁽¹⁾

- Pharmacists providing anticancer drugs have to take care of multiple side effects such as adverse drug reactions, effective medication administration support, therapeutic drug monitoring as well as assuring medication adherence by the patient.

Guidance to support clinical verification of oncology drugs⁽²⁾

- British Oncology Pharmacy Association (BOPA) has published standard guidelines for pharmacists to follow for comprehensive verification.

Supporting evidence from literature



1. [Carolyn SJ Ma, Role of pharmacists in optimizing the use of anticancer drugs in the clinical setting, Dec 2013](#)
2. British Oncology Pharmacy Association, Guidance to support BOPA standards for clinical pharmacy verification of prescriptions for cancer medicines, Feb 2012



Providing and coordinating continued staff training



What is the challenge?

The effective management of haematological malignancies require a team of specialists, who are able to integrate specific expertise (e.g. diagnostics, haematology). The continued progress in the treatment and management of these set of conditions in recent years means these specialists require regular and continued access to newest evidence based findings, procedures and thinking in order to formulate optimal treatment plans for patients.

What is the initiative?



Which patient is it for?

- All patients across the patient journey.

Which staff members are involved?

- Haematologists haemato-pathologist, imaging specialists, dentists etc.

What is offered as part of this initiative?

- Formal workshops (international, national or regional).
- Continuous professional development:
 - Formal local sessions for knowledge sharing or peer-learning;
 - Rotational programmes.

What have we observed?



What are the objectives?

- To broaden knowledge and skills.
- To provide structured programmes for continued learning and support.

How was it achieved?

- Setting up regular, structured workshops:
 - Structured, regular meetings for physicians and diagnostic teams dedicated to education on haematological malignancy topics (e.g. CLL, MM & CML);
 - Forum for sharing knowledge, discussing treatment guidelines, good practices and discuss interesting cases;
 - Usually a leading physician (national/international) is invited to attend and speak at workshops;

- An option is to use industry to sponsor these events (e.g. venue, planning and logistics).

- Implementing options for continued professional development:
 - International (e.g. Latin America wide) rotational programmes for haematologists, nursing and diagnostic teams spend a number of months in residence;
 - National or local working groups for peer-learning (e.g. academic discussions on specific topics, good practice in patient management);
 - In-hospital peer-learning sessions (e.g. morbidity and mortality sessions).

What are the potential outcomes?



Clinical

- Broader understanding of haematological malignancies and optimal management techniques.
- Opportunity to develop networks and relationships.



Patient experience

- Better service of care.
- Implementation of novel treatment paradigms.



Selected case studies



Industry-sponsored national training programmes – Fundaleu, Argentina (see site visit report)

Specialist training workshops for haematologists and diagnostic technicians to disseminate recent findings and educate on good practice care.



Rotational programme for regional HCPs – Fundaleu, Argentina (see site visit report)

Rotational programme for haematologists, nurses and diagnostic staff to spend one-three months at Fundaleu.



'Best practice' network for oncology – Americas Centro de Oncologia Integrado, Brazil (see site visit report)

Working sessions with haematologists from leading centres across Brazil to discuss protocols and good practice in patient management.

Additional options from other centres/global published literature



Regular classroom training (Mayo Clinic, USA)⁽¹⁾

— Multiple classroom courses for all HCPs involved in haematological malignancy care are conducted. These cover the whole treatment pathway, and are conducted from focused one day sessions to comprehensive week long training sessions.

Attendance at international conferences (National Comprehensive Cancer Network (NCCN))⁽²⁾

— Regular attendance at relevant conferences (e.g. ASH or NCCN) can help physicians to expand their knowledge. An option would be to use industry as a funding source for expenses at these events.

Supporting evidence from literature



1. [Mayo Clinic: Mayo Clinic School of Continuous Professional Development, HM Courses](#)
2. [NCCN: NCCN 13th Annual Congress: Hematologic Malignancies, Overview](#)



What is the challenge?

Regular monitoring of the quality of care provided would enable centres to assess the impact of their processes and programmes in place, and identify means of improving outcomes. Challenges with implementation include the need for part time or full-time dedicated personnel to manage quality programmes; and instilling a culture of awareness and dedication to quality across the hospital and care teams.

What is the initiative?



Which patient is it for?

- All patients will benefit.

Which staff members are involved?

- Either dedicated or part time quality management teams (may be composed of physicians or nurses, with administrative support).

What is offered as part of this initiative?

- Structured programmes for tracking and improving quality and safety.
- Programme for robust collection of relevant outcomes across impactful categories.

What have we observed?



What are the objectives?

- Improve patient outcomes.
- Better manage hospital resources.

How was it achieved?

- Implementing structured quality and safety management programmes:
 - Top down commitment to capture of quality metrics;
 - Implementing a dedicated team/individual for management of quality programme;
 - Developing required tools (e.g. databases, reporting forms, web interfaces);
 - Agreeing on a set of relevant metrics for regular monitoring of quality and safety (e.g. haematological malignancy outcome measures in line with national or international guidelines, patient falls, infection rates, co-morbidities post-transplant, neutropenic fever etc.);

- Establishing structured and regular meetings for sharing of quality/safety data and agreeing on improvements (e.g. monthly morbidity-mortality meetings, one-on-one sessions with relevant teams).

What are the potential outcomes?



Clinical

- Improved outcomes due to higher investment in quality of service provided (e.g. reduced infections, patient falls etc.).



Patient experience

- Increased sense of safety.
- Increase level of trust in care received.



Selected case studies



Patient signposting – Hospital Universitario Austral, Argentina (see site visit report)

A detailed signposting system is on the door of each patients' room, which details key aspects of the patient to enable rapid identification and improving patient safety.



Quality control – Hospital Universitario Austral, Argentina (see site visit report)

Hospital wide comprehensive programme for monitoring multiple quality and safety metrics, which are reviewed monthly and used to drive improvements in patient and clinical outcomes.



Quality programme – Hospital Maciel, Uruguay (see site visit report)

Implementation of a structured programme of quality improvements across initially the BMT service, but effectively to all functions of the haemato-oncology unit. The goal of the programme is to ultimately improve patient outcomes and hospital resource management.



We are aiming to get the job well done each time. I am very happy to be part of this culture and strongly believe in its worth, and the impact it has on the hospital, patients and healthcare workers.

Quality control, Hospital Austral, Argentina

Additional options from other centres/global published literature



Chemotherapy administration safety standards⁽¹⁾

— Some of the safety standards include: creating a safe environment, treatment planning, patient consent and education.

Improving patient safety in clinical oncology following an algorithm based on Normal Accident Theory (NAT)⁽²⁾

— The University of North Carolina applied a protocol for patient safety in oncology developed from NAT and observed improved outcomes such as reduced wait time, reduced percentage of patients requiring radiation therapy re-planning.

Supporting evidence from literature



1. [Michael N. Neuss et al., 2016 Updated American Society of Clinical Oncology/Oncology Nursing Society Chemotherapy Administration Safety Standards, Including Standards for Pediatric Oncology, 2017](#)
2. [Bhishamjit S. Chera et al., Improving patient safety in clinical oncology applying lessons from Normal Accident Theory, Jun 2015](#)



What is the challenge?

Haematological malignancy patients often undergo high intensity and lengthy treatments (e.g. high dose chemotherapy for induction of remission, BMT) that have a strong impact on physical and mental well-being. It also has an impact on patient and carer quality of life. Ensuring patients and carers are well equipped to manage the realities of an haematological malignancy diagnosis and its treatment can improve adherence and therefore clinical outcomes. Integrative care is critical to ensuring patients are both physically and mentally supported throughout their journey.

What is the initiative?



What have we observed?



Which patient is it for?

- All patients across the patient journey.

Which staff members are involved?

- Providers of integrative (e.g. psychology, nutrition, dentistry, rehabilitation) services.

What is offered as part of this initiative?

- Structured or on-demand/ad hoc processes for provision of integrative services (e.g. psychologists, dentists, nutritionists etc.)
- Structure or on-demand provision of optional additional integrative services (e.g. music or art therapy, yoga, massage etc.)

What are the objectives?

- To better understand patient state of mind and ability to withstand treatment.
- To provide holistic support to patients and support in maintaining mental health and well-being.
- To support family/carers and ensure they are supported as needed.

How was it achieved?

- Structured or on-demand/ad hoc provision of integrative services:
 - Regular (e.g. daily/at start of treatment) face to face meetings with psychologist or psycho-oncologist for patient and family);
 - Regular check up of patient by dentists/dieticians (e.g. prior to BMT).

- Structure or on-demand provision of optional additional integrative services:
 - Rehabilitation sessions (e.g. music therapy, massage, reflexology, art);
 - Bereavement counselling.
- Advanced options include:
 - Delivery of services free of charge to patient and family (often not reimbursed through private or public Payers);
 - Evidence-based selection of activities using peer-reviewed publication demonstrating clinical/patient reported benefits.

What are the potential outcomes?



Clinical

- Improved adherence to treatments.



Patient experience

- Better and faster recovery times.
- Better mental state, allowing for physical improvement.
- Patients feel connected to family, which is reported as a very important factor in their care.



Selected case studies



Integrated oncology support services – Fundaleu, Argentina (see site visit report)

Offers services to patients free of charge (funded entirely by Fundaleu Foundation), including acupuncture and reflexology aimed at improving mental well-being.



360 degree psychologist support – Clinica Colombia Colsanitas, Colombia (see site visit report)

Psychologist support is given to patients and their families, in addition to providing this service to healthcare providers to help them deal with issues arising from the job.



Psychological support – Hospital Regional de Alta Especialidad de Ixtapalua, Mexico (see site visit report)

Psychologist who works closely with all haematological malignancy patients, with priority given to high-risk patients (e.g. pregnant women).



Psycho-oncology support – Instituto Nacional de Cancerología, Mexico (see site visit report)

Psycho-oncologist specialising in haematological malignancy, who conducted structured meetings (weekly meetings with acute patients; monthly or before and after key treatments with chronic patients) and collaborate closely with haematologists.



Animal-assisted therapy - ICESP, Brazil (see site visit report)

Programme aimed at improving the patient's wellbeing by patients to see their pets, or to interact with the hospital's own dogs within a safe, monitored environment.

Additional options from other centres/global published literature



Rehabilitation therapy for BMT patients^(1,2)

— Literature suggests an improvement in outcomes and survival rates of BMT patients when they are introduced to specific rehabilitation therapies for patients undergoing transplantation. These include activities focused on inflammation, fatigue and exercise.

Clinical partnerships to offer integrated and supportive services^(3,4)

— In the USA the Moffitt Cancer Centre has partnered with the Memorial Healthcare System to offer integrated treatment to patients for physical, mental and emotional well-being.

— In Canada McGill has initiated a Cancer Nutrition Programme and partnered with the Segal Cancer Centre, Jewish General Hospital and MUHC-Royal Victoria Hospital and provide their cancer patients with nutritional rehabilitation therapies.



Patient care and support is the primary goal. All the staff are very close to the patients and their families.

Haematologist, Fundaleu, Argentina

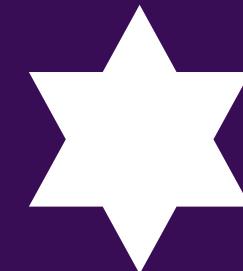
Supporting evidence from literature



1. Importance of physical rehabilitation in stem cell transplantation patients evidenced from many centres such as Mayo Clinic, MD Anderson Cancer Center etc.
2. [Amir Steinberg et al., The role of physical rehabilitation in stem cell transplantation patients, Aug 1, 2016](#)
3. [Memorial Healthcare System: Moffitt Cancer Center to provide cancer services at Memorial Healthcare System in South Florida, May 01, 2017](#)
4. [McGill: Cancer Nutrition Rehabilitation Program, Clinical care](#)



Providing high-quality medical
management

A blue circle containing the number '4' in white.



Delivering rapid and accurate diagnosis



What is the challenge?

Establishing a differential diagnosis of haematological malignancy is complex, as they often have overlapping clinical presentations, requiring precise identification and accurate staging to develop appropriate treatment plans. This requires the use of multiple testing platforms (e.g. cytogenetics, cytomorphology, molecular pathology etc.) and specialist staff (e.g. haemato-pathologists). Often, rapid diagnosis is required (e.g. for patients with potential acute disease). Ability to integrate and interpret data, produced in house or through a network of laboratories, is important for accurately and timely diagnosis.

What is the initiative?



What have we observed?



Which patient is it for?

- All patients, but particularly those with rapidly progressing forms of haematological malignancy.

Which staff members are involved?

- Pathologists; with access to specialist MDTs, clinical laboratory technicians.

What is offered as part of this initiative?

- Integrated laboratory services including haemato-pathologist.
- Established networks for high-quality diagnostics (specialist staff and facilities).

What are the objectives?

- To reduce time to diagnosis.
- To reduce number of misdiagnoses.

How was it achieved?

- Integrated laboratory services including haemato-pathologist:
 - Co-location of most diagnostic platforms and expertise at a single site, with protocols for specimen handling, diagnostic pathways and reporting;
 - Presence of a haemato-pathologist, and other specialised capabilities (e.g. imaging), who work within the MDTs to manage patients.
- Established networks for access to high-quality diagnostics (specialist staff and facilities):

- Building relationships with specialist haemato-pathologists for referral of complex specimens;
- Identifying and establishing network of diagnostic labs to provide consistent and high-quality diagnostic work ups.

What are the potential outcomes?



Clinical

- Timely and accurate diagnosis resulting in ability to better manage treatment.



Patient experience

- Improved patient experience through short time to diagnosis.
- Improved patient QoL through faster access to treatment.



Selected case studies



Haematopathology specialism – Fundaleu, Argentina (see site visit report)

In-house haematopathologist, who works within the MDT to manage patients. Also runs a training programme for haematopathologists in the region; and provides free-of-charge second opinion on diagnoses.



Specialised haemato-oncology imaging services – Fundaleu, Argentina (see site visit report)

Imaging specialist with training in haematology, who is able to provide follow up on all related complications.



Centralised screening and alarm system – Clinica Colombia Colsanitas, Colombia (see site visit report)

Centralised laboratory service screening samples nationally and expediting linkage to care when abnormalities are detected.



Patient regulation – ICESP, Brazil (see site visit report)

ICESP developed a standardised form in order to ensure accurate diagnosis of haematological malignancy. This was adopted by the State Department of Health and has been rolled out across Sao Paulo to ensure that patients arrive at the hospital with a correct diagnosis.

Additional options from other centres/global published literature



Network of high-quality diagnostic laboratories (Americas Centro de Oncologia Integrado, Brazil)

- Americas Centro de Oncologia Integrado has established a network of laboratories that provide consistently high-quality diagnostic results, thereby minimising time and errors of misdiagnosis/repeated sampling.

Implementing specialist integrated haematological malignancy diagnostic services^(1, 2)

- Establishing a single site diagnostic laboratory with organisation structures, single quality management system with pre-defined diagnostic pathways. Literature suggests haematopathology specialty laboratories result in earlier and more accurate diagnosis with reduced need for follow-up testing.



It should be common for pathologists to work in haematology courses through the haematology society. It is key for haematologists to understand what exactly they need to send to pathologists, so close communication is essential.

Chief of Pathology, Fundaleu

Supporting evidence from literature



1. [Integrated diagnostic reporting: Haematological cancers: improving outcomes. NICE guidelines, published May 2016](#)
2. [Nicole M Engel-Nitz et al., Diagnostic testing managed by hematopathology specialty and other laboratories: costs and patient diagnostic outcomes, 2014](#)



Using clinical trials to support patient care and treatment



What is the challenge?

Participation in clinical trials enables centres to capture reliable evidence on the effectiveness of the initiatives and they also provide means of access to novel therapeutics current not available to the patient population. However, many centres may not see sufficient number of patients per year to justify a clinical trial, nor may they have the required infrastructure, tools and processes in place that would enable them to conduct trials. Further, not all centres will be well known to industry, and therefore may not have priority as a clinical trial site.

What is the initiative?



Which patient is it for?

- Patients in clinical management, particularly those requiring novel or expensive medications.

Which staff members are involved?

- Mainly haematologists and clinical nurses.

What is offered as part of this initiative?

- Running clinical trials in house:
 - Creation of capabilities (e.g. dedicated unit) in house;
 - Prioritising use of clinical trials.
- Access to clinical trials through building networks with larger, regional centres.

What have we observed?



What are the objectives?

- To develop skills, tools and infrastructure needed to run large scale clinical trials.
- To build a network within the region to improve referrals of patients to centre for clinical trials.
- To improve access for patients to novel medication not currently reimbursed/which the patient is not able to afford.
- To capture outcomes and build understanding of effectiveness of initiatives.

How was it achieved?

- Creation of a dedicated unit to run clinical trials:
 - Hiring dedicated staff members for key roles (e.g. data manager, statistical manager, clinical trial nurses);

- Building required tools and processes (e.g. databases, good clinical practice);
- Establishing or building access to required expertise (e.g. ethics committees, regulatory bodies);
- Collaborating with international centres (e.g. multi-centre trials) and designing outcome measures that reflect clinical measures with prognostic significant, survival times and QoL (patient reported);
- Publication of findings in a timely manner to build reputation and engage with industry for further trials.
- Prioritising use of clinical trials for access to novel or prohibitively expensive medicines:
 - Requirement placed on all staff to conduct clinical trials;
 - Building networks with regional hospitals to develop patient referral schemes.

What are the potential outcomes?



Clinical

- Improved clinical outcomes due to access to novel therapeutics/improved care.

Patient experience

- Greater satisfaction at being able to access new drugs.
- Improved engagement due to ability to contribute to outcome measures (e.g. QoL).



Selected case studies



Access to novel medicines – Instituto Nacional de Cancerología, Mexico (see site visit report)

A dedicated unit for clinical trials, with requirement from all staff to run protocols, supported by very close links to industry.



Clinical Investigation Centre – Hospital Maciel, Uruguay (see site visit report)

Developing suitable clinical trial infrastructure and gain experience of clinical trials through commencement and running of Investigator-initiated trials (IIT). This will enable Haematology Maciel to eventually take part in industry sponsored trials, allowing patient access to novel drugs not currently reimbursed through the Administracion de los Servicio de Salud del Estado (ASSE).



Medicine access through clinical trials – Hospital Ángele Lomas, Mexico (see site visit report)

Process in place for identification of eligible patients from public hospitals for clinical trials in-house, enabling wider access to medicines.

Additional options from other centres/global published literature



Compassionate use programmes across numerous centres visited

Collaborative clinical trial department (University College London (UCL) Cancer Institute and UCL Hospitals Foundation Trust, UK)⁽¹⁾

- Setting up close collaborations with renowned institutes can support an increase the number of trials conducted. Additionally this provides a division of labour (resources and funding) between all participating institutes.

Supporting evidence from literature



1. [UCL Cancer Institute, Department of Clinical Trials](#)



Enhancing the linkage between the Intensive Care Unit (ICU) and the haematology department



What is the challenge?

The intensity of treatments for haematological malignancies, including high dose chemotherapy and BMT, mean patients often become critically ill. Historically, there has been a perception that these patients have a poor prognosis and therefore a reluctance from clinicians to admit them to the ICU. This is aligned with the stigma that once a patient is transferred to the ICU, the likelihood of them returning to the haematology ward is low. However, recent advances in care (see literature review section) have indicated better outcomes, therefore initiatives that enable earlier ICU access to those patients who are likely to benefit may improve overall outcomes.

What is the initiative?



What have we observed?



Which patient is it for?

- Critically ill patients (e.g. pulmonary complications resulting in requirement for assisted ventilation).

Which staff members are involved?

- Haemato-oncologists, intensive care unit, clinical nurse team.

What is offered as part of this initiative?

- Active transfer of patients to ICU earlier (i.e. before condition considered 'critical').
- Rapid access to ICU capabilities through mobile units or dedicated rooms within ward/outpatient unit.

What are the objectives?

- Provide ICU facilities to the patient in adequate time.
- Maintain continuity of care; through continued presence of haematologists and nursing staff.

How was it achieved?

- Active and early transfer to the ICU:
 - Training to improve understanding of requirements for ICU transfer (e.g. haematology residents required to work 3 months in ICU during training);
 - Close liaison and agreement with ICU on guidance for early transfer.

— Mobile ICU facilities :

- Capabilities (e.g. mechanical ventilators) that enables each bed to be converted to an ICU facility;
- Dedicated staff (e.g. clinical nurse with ICU training/ICU physicians) able to manage patient, e.g. nurse with dual training in haematological malignancies and ICU becomes 100% dedicated to critically ill patient.

— Dedicated ICU rooms within ward/outpatient unit

- Availability of 1-2 ICU rooms within out-patient or in-patient facility for managing critically ill patients;
- Ability to access ICU physicians and nurses at short notice.

What are the potential outcomes?



Clinical

- Improved prognosis for critically ill patients.



Patient experience

- Patient and family satisfaction at provision of ICU care to patient.



Selected case studies



Earlier intervention of the ICU unit – Hospital Maciel, Uruguay (see site visit report)

Active intervention to increase the coordination of care between haematology and ICU. Specifically this seeks to bring involvement of the ICU into the patient journey at an earlier stage.



ICU to the patient – Fundaleu, Argentina (see site visit report)

All patient rooms in Fundaleu have the ability to accommodate mobile ICU facilities, effectively 'bringing the ICU to the patient'. This means the patient remains in the same care setting, maintaining the same staff team.



ICU rapid intervention and quality control – Hospital Ángeles Lomas, Mexico (see site visit report)

Process for prioritisation of patients in need of critical care and system of metrics to track and monitor outcomes.



Early anticipation of ICU requirement and psychological preparation – ICESP, Brazil (see site visit report)

Anticipatory assessment and identification of patients who are more likely to be admitted to intensive care during their care means that physicians can adequately prepare both the patients and their family explaining processes and treatment protocols that will be required.

Additional options from other centres/global published literature



Dedicated ICU room within outpatient unit (Americas Centro de Oncologia Integrado, Brazil)

- A dedicated room containing ICU facilities are available for rapid treatment of patients who become critically ill during chemotherapy.

Coordination among ICU consultant and haematological malignancy consultant is important for ICU referral⁽¹⁾

- It is recommended to have direct discussions before referral for ICU for haematological malignancy patients, to ensure safe transfer and improved outcomes for patients.



Before this initiative was established, most patients would die in the ICU. This is about removing the stigma that they will not come back.

Haemato-oncologist, Hospital Maciel, Uruguay

Supporting evidence from literature



1. [Matt P. Wise et al., Guidelines on the management and admission to intensive care of critically ill adult patients with haematological malignancy in the UK, Aug 19, 2015](#)



Providing personalised medicine



What is the challenge?

While standard treatments (e.g. chemotherapy) have been largely effective across the haematological malignancy patient population, advances in targeted inhibitors (e.g. PI3K targeted therapies, BCL-2 targeted therapies) combined with targeted antibodies (e.g. anti-CD-20) has resulted in greater focus on personalised medicines based on individual molecular and genetic profiles. However, patient suitability for personalised treatments requires expert knowledge and access to expensive technologies (e.g. Next generation sequencing).

What is the initiative?



What have we observed?



Which patient is it for?

- All patients.

Which staff members are involved?

- Haemato-oncologists, haemato-pathologists, geneticists.

What is offered as part of this initiative?

- Patient management by highly-specialised teams.
- Access to technologies for more accurate diagnostic and prognostic markers.

What are the objectives?

- To provide tailored treatment to patients.
- To improve clinical outcomes.

How was it achieved?

- Developing specialised knowledge on valuable prognostic indicators by indication:
 - Collaboration to bring together leading experts (national and international) to develop capabilities (e.g. biological capabilities or protocols for prognostic evaluation);
 - Establishment of IITs, sharing resource and funding requirements to strengthen knowledge and understand impact on outcomes.
- Collaborating for access to new technologies (e.g. next generation sequencing):

- Developing specialised networks for access to expensive technologies, such as genomic sequencing;
- Networks can additionally be leveraged to access expertise.

What are the potential outcomes?



Clinical

- Improved diagnostic and prognostic capabilities, allowing delivery of medication leading to improvements in clinical outcomes.



Patient experience

- Greater awareness and understanding of condition.



Selected case studies



Access to genomic sequencing – Fundaleu, Argentina (see site visit report)

Collaboration with CEMIC University Institute in Buenos Aires, Argentina to access genomic sequencing (Sanger sequencing).



Indication specific expert working group – Americas Centro de Oncologia Integrado, Brazil (see site visit report)

Working groups focused on specific indications in haematological malignancies are run every two weeks; providing opportunities to discuss indication specific patient management.



CLL working group – Hospital Maciel, Uruguay (see site visit report)

Working group with individuals across Uruguay, Argentina and Brazil to develop biological capabilities and protocols for patients with CLL, identifying biomarkers for risk stratification.

Additional options from other centres/global published literature



Dedicated Departments for more personalised care (MD Anderson Cancer Center, USA)⁽¹⁾

- The centre has a dedicated leukemia, lymphoma and myeloma departments, where experts can provide specialised care.

Collaboration with NGOs for access to targeted therapy⁽²⁾

- Novartis launched a drug donation campaign in partnership with an NGO called Max Foundation to distributed Imatinib for treatment of CML to nearly 49,000 patients over 14 years (since 2001) to a variety of low-income countries.

Clinical Practice Guidelines in Oncology adding targeted therapy (National Comprehensive Cancer Network (NCCN) guidelines)⁽³⁾

- Guidelines for use of targeted therapies for leukemia and lymphoma highlighting key recommendations for specific patient groups (younger or older).

Personalised medicine for haematology is in early stages⁽⁴⁾

- It highlights the usefulness of targeted therapies (which have higher efficacy in comparison to chemotherapy) and existing challenges in the sector.

Supporting evidence from literature



1. [MD Anderson Cancer Center, Care Centers and Clinic](#)
2. [Garcia-Gonzalez P et al., Novel Humanitarian Aid Program: The Glivec International Patient Assistance Program—Lessons Learned From Providing Access to Breakthrough Targeted Oncology Treatment in Low- and Middle-Income Countries, Oct 2015](#)
3. [Targeted Oncology, NCCN Guidelines Updates: Hematologic Malignancies, 2013](#)
4. [Gayane Badalian-Very, Personalized medicine in hematology — A landmark from bench to bed, 2014](#)



Establishing high-risk group management



What is the challenge?

Due to the nature of haematological malignancies there are subgroups of individuals who are particularly susceptible to contracting the disease or are likely to have a worsened prognosis once they develop haematological malignancies. There is a strong genetic linkage in many cancers, leaving individuals predisposed to the disease. Other high-risk individuals may be susceptible to increased risk of complications. These categories of individuals need to have specialised care and are to be monitored very closely with tailored treatment programmes to ensure survival and best outcomes possible for the patient group.

What is the initiative?



What have we observed?



Which patient is it for?

- High-risk individuals such as those with genetic predispositions, autoimmune diseases, pregnant patients etc.

Which staff members are involved?

- All core team: haematologists, haemato-pathologists, nurses, transplant team members including clinical oncologists, radiotherapists, palliative care specialists, radiotherapists, pharmacists, psychologists, dieticians, dentists and allied professionals (e.g. social care, rehabilitation specialists). Specialist requirements from geneticists.

What is offered as part of this initiative?

- Individualised/specialised care
- Screening and continual testing
- Awareness and education programmes

What are the objectives?

- To diagnose haematological malignancy at an earlier date.
- To provide timely access to the correct treatments.
- To effectively manage treatment of high-risk individuals:
 - Offer the best therapeutic option for the patient;
 - Decrease mortality rates.

- Integrated care and communication between physicians across the treatment pathway to effectively manage the care of the high-risk patient, ensuring full understanding of the complications and requirements.

How was it achieved?

- Regular genetic testing of patients with suspected abnormalities or of those who are suspected to be at high risk (as well as their families).
- Training of geneticists, and availability onsite to speak to patients.

What are the potential outcomes?



Clinical

- Better treatment outcomes and higher survival rates of high-risk individuals.



Patient experience

- Personalised and tailored care leading to greater patient satisfaction.
- Patient trust and security throughout treatment.



Selected case studies



CREHER clinic – Hospital Regional de Alta Especialidad de Ixtapaluca, Mexico (see site visit report)

Specialist clinic created for pregnant women suffering from haematological malignancies. There are limited capabilities for the management of pregnant patients with cancer often resulting in termination of pregnancy. This clinic allows for specialised care for the mother and the baby are held with equal importance.



High risk cancer screening programme – Instituto Nacional de Cancerología, Mexico (see site visit report)

Dedicated hereditary cancer risk centre set-up to identify and track high-risk individuals. Free screening is offered for patients with suspected genetic abnormalities.



Early anticipation of ICU requirement and psychological preparation – ICESP, Brazil (see site visit report)

Anticipatory assessment and identification of patients who are more likely to be admitted to intensive care during their care means that physicians can adequately prepare both the patients and their family explaining processes and treatment protocols that will be required.

Additional options from other centres/global published literature



Older Adult Hematologic Malignancy Programme (Dana Farber Cancer Institute, USA)⁽¹⁾

— Elderly patients with haematological malignancies get specialised care across the treatment pathway from an oncologist from the Dana Farber Institute and a geriatrician from the Brigham and Women's Hospital Division of Aging.

HIV patients at risk for haematological malignancies⁽²⁾

— HIV patients are at very high risk of developing haematological malignancies and need special care (due to high chances of infection). These patients can greatly benefit from stem cell transplant.

Two half-day HIV Clinic (Keck School of Medicine of University of Southern California, USA)⁽³⁾

— The centre holds two half day clinics dedicated specifically for HIV patients with haematological malignancies. This is run by two full-time HCPS from the haematology faculty.

Supporting evidence from literature



1. [Dana Farber Cancer Institute, Research Spotlight: Older Adult Hematologic Malignancy Program](#)
2. [Joseph C. Alvarnas et al., How I Treat Patients with HIV-Related Hematological Malignancies using Hematopoietic Cell Transplantation, Sep 2017](#)
3. [Keck School of Medicine of USC, Patient Care, Clinical functions of the Division of Hematology within the Department of Medicine include: Facilities](#)



Case study

Hospital Regional de Alta Especialidad de Ixtapaluca's dedicated clinic for cancer in pregnancy aims to provide integrated care to both the mother and the foetus

Existing challenge



Mexico has a high maternal mortality rate and cancer is the second most common obstetric indirect cause of death.

1 in 1,000 pregnancies is associated with cancer...
of which 25% are haematological, 26% are breast and 26% are cervical uterine cancer.

There are currently no specialised clinics offering holistic care and management for pregnant women with cancer in Mexico.
Often the result without this support is the premature ending of pregnancy.



Initiative



Overview

HRAEI's dedicated clinic [Clínica de Referencias de Enfermedades Hemato-oncológicas en el Embarazo (CREHER)] is a highly-specialised clinic catering to pregnant women suffering from cancer.

They provide holistic care for both the mother and foetus, providing cancer treatment as well as ensuring a safe pregnancy and delivery. The clinic was initiated in May 2016, and to date has delivered care to 10 patients (July 2017).



I was an in-patient for 12 days and everyone took care of me. I had other opinions that said you are crazy to get chemotherapy while pregnant. But here I was taken care of and here [baby] is the living product that it can work.

CREHER clinic patient (translated from Spanish)

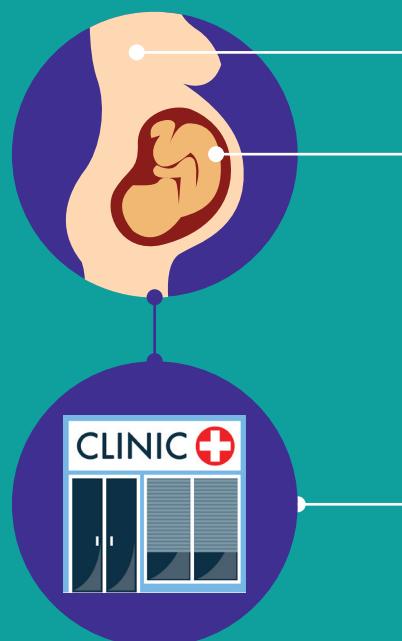


Objective



To give integrated care to women with the diagnosis or suspicion of any type of cancer, at any stage of pregnancy. The patients may be referred from centres across Mexico which do not have the necessary capabilities for diagnosis, treatment and follow-up of the binomio (mother – foetus).

The clinic has multiple goals:



- **For mother:** To offer the best therapeutic option for each specific type of cancer during pregnancy.
- **For foetus:** To favour pregnancy with limited harm to the foetus and oversee its development to term.
- **Institutional:**
 - To review, systemise and generate knowledge on the diagnosis and treatment of cancer in pregnancy, and to share these widely.
 - To contribute in the decrease of indirect obstetric mortality in Mexico.

Team



CREHER clinic was born by the need to offer holistic treatment for pregnant women with leukemic conditions. In the first phase it was focused on haematology, oncologic genecology and maternal foetal medicine; these specialties established the basis for the clinic and created an integrated multidisciplinary team which includes administrative, legal and healthcare team.

There is a multidisciplinary team of over

30

specialists involved in delivering care to the patient.



Source: Presentación de la Clínica CREHER , 2017 (Shared by the hospital)



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Improvement in the management of haematological malignancies | 98



Case study (cont.)

There is a well-developed process in place to guide the patient throughout the gestation period

Key features



Patients referred to the CREHER clinic are highly vulnerable and reliant on the hospital's support.

Therefore they are provided with priority access to all services throughout the hospital during their care.

Once the team is aware of the specific conditions for the case, the first approach to the patient is by social workers and psychologists, to learn about their support social network and their emotional state; they assess the women's feeling towards her condition and whether they would like to continue with the pregnancy.

Prior to arrival in the clinic, the patient information is disseminated via a WhatsApp group to the full CREHER clinic team, allowing for adequate preparation and advanced knowledge of any complex cases. Each case is reviewed individually to assess treatment paradigm based on risks. The foetus is treated as a patient with its own rights, and a specific care plan is created.

"We pay equal attention to the foetus. The foetus is a patient and we care for them like a patient" – **Obstetrician**

In all cases of high-risk patients, the whole MDT team attends the obstetrics unit to assess and decide on the approach for treatment continuation. The clinic operates a very close relationship with the gynaecology/obstetrics team.

Following discharge, all babies and their mothers are followed up for five years.

"Give a little bit more than you need to, every day" – **Chief, haemato-oncology**

Source: 'Presentación de la Clínica CREHER', 2017 (Shared by the hospital)

The clinic follows a process to support the patient from the first contact throughout the gestation period:



The process has been replicated per the information gathered from the CREHER clinic.





Case study (cont.)

To date, the CREHER clinic has consistently met its targets for KPIs, including time to diagnosis and initiation of treatment

Potential impact:

Key parameters for measurement of efficiency

The CREHER clinic has had 10 patients, and has resulted in the successful delivery of eight healthy babies.

Key Performance Indicators (KPIs) definition for measuring efficacy	Formula		
<p>1 Time interval between the reference and the initial assessment of the gestational cancer quotient or time between first meeting and diagnosis.</p>   	$\frac{\text{No. of pregnant patients with } <30 \text{ days between imaging/anatomo-pathological diagnosis, of neoplastic process and the initial evaluation}}{\text{Number of pregnant patients undergoing initial treatment of any neoplastic process}} \times 100$		
<p>2 Time interval between definitive diagnosis and initiation of cancer treatment in pregnancy.</p>   	$\frac{\text{Number of pregnant patients with cancer treated within } <1 \text{ month from the definitive diagnosis}}{\text{Total number of pregnant patients with definitive diagnosis of cancer}} \times 100$		
Key learnings for replication:			
	<p>Align all staff involved in the care of the patient on the needs of both the mother and the foetus. Gain a consensus on the ways of working in the future, to ensure the creation of a dedicated and cohesive clinic.</p>		<p>Provide additional training where specialist knowledge is required, such as for psychologists, nurses, support staff in managing pregnant oncology patients, minimising the associated stigma etc.</p>

Source: 'Presentación de la Clínica CREHER', 2017 (Shared by the hospital)



Target outcome	Actual outcome achieved	Comments
10 days	2 days	<ul style="list-style-type: none">— The elapsed time is related to the centre's own therapeutic diagnostic circuits, and the patient referral system.— Delay in commencement of the treatment may imply modifications in the progress of the cancer in addition to the anguish on the part of the patient.— After diagnosis, the treatment start time should not exceed one month, which is the limit that makes a clear difference in risk status.— It aims to publish the outcomes from the treatment and management of pregnant patients, in collaboration with other centres and specialists to increase the visibility of the clinic.
10 days	6 days	



Agree and implement a series of metrics for assessing impact.



Collaborate across institutes to share best practices and learnings.



Establishing infection control programmes



What is the challenge?

Patients suffering from haematological malignancies can be severely immunocompromised due to their treatment and medication. Therefore it is essential to have programmes in place that help to reduce/minimised infection rates. Buy-in from all hospital physicians is essential in ensuring effective management. Education on hygiene and general cleanliness for hospital staff as well as patients is essential in ensuring awareness of the risks and consequences. Education can also help patients manage their care in the outpatient setting as well.

What is the initiative?



What have we observed?



Which patient is it for?

- Patients receiving treatment or hospitalised.

Which staff members are involved?

- Specialist infection HCPs, dedicated nurses, cleaners etc. All staff are required to play a role in reducing infection rates.

What is offered as part of this initiative?

- Ensuring cleanliness of hospital.
- Education and training of staff about protocols.
- Monitoring of physician adherence to infection prevention and control protocols.
- Education of patients and families on prevention initiatives.

What are the objectives?

- To reduce infection rates:
 - Inpatients;
 - Outpatients.
- To deliver education to patients and families around infection prevention.

How was it achieved?

- Effective tracking of infection control metrics with comprehensive databases:
 - Effective processes in place to consistently monitor and capture data.
- Training of infection control specialist doctor and nurses.
- Dedicated cleaning team all with established protocols for cleaning.
- Development of educational materials and provision of forums and platforms where this information can be shared.

What are the potential outcomes?



Clinical

- Lower infection rates.
- Higher survival rates.



Patient experience

- Quicker recovery time.



Selected case studies



Infection control - Hospital Universitario Austral, Argentina (see site visit report)

A dedicated infection control team who educate, monitor and ensure infection control across the hospital, contributing to high-level patient safety.



Early anticipation of ICU requirement and psychological preparation – ICESP, Brazil (see site visit report)

Anticipatory assessment and identification of patients who are more likely to be admitted to intensive care during their care means that physicians can adequately prepare both the patients and their family explaining processes and treatment protocols that will be required.



We want to continue to do more to capture and establish impact of our processes and share these, so other centres can learn from this as well.

Infection control nurse, Hospital Austral, Argentina

Additional options from other centres/global published literature



Infection Prevention in a cancer centre⁽¹⁾

- Cancer patients are susceptible to multiple infections and many of them can be easily avoided by undertaking some preventative measures such as: simply the early identification of infections, optimised antimicrobial usage, and implementing and educating patient around certain practices of hygiene.

Infection control from Multidrug-Resistant Organisms⁽²⁾

- Prolonged chemotherapy and hospital visits make haematological malignancy patients susceptible to severe infections and these are can be monitored and managed by the HCPs, patients and their families/carers.

Supporting evidence from literature



1. [Kerri A. Thom et al., Infection Prevention in the Cancer Center, May 2013](#)
2. [Ella J Ariza-Heredia and Roy F Chemaly, Infection Control Practices in Patients With Hematological Malignancies and Multidrug-Resistant Organisms: Special Considerations and Challenges, Sep 2014](#)



Case study

Hospital Universitario Austral has a dedicated Prevention and Infection Control unit for development and implementation of quality care practices

Existing challenge



Patients requiring care can be highly susceptible to infection. This is especially apparent during the treatment of haematological malignancies, due to the immunocompromised nature of many patients.

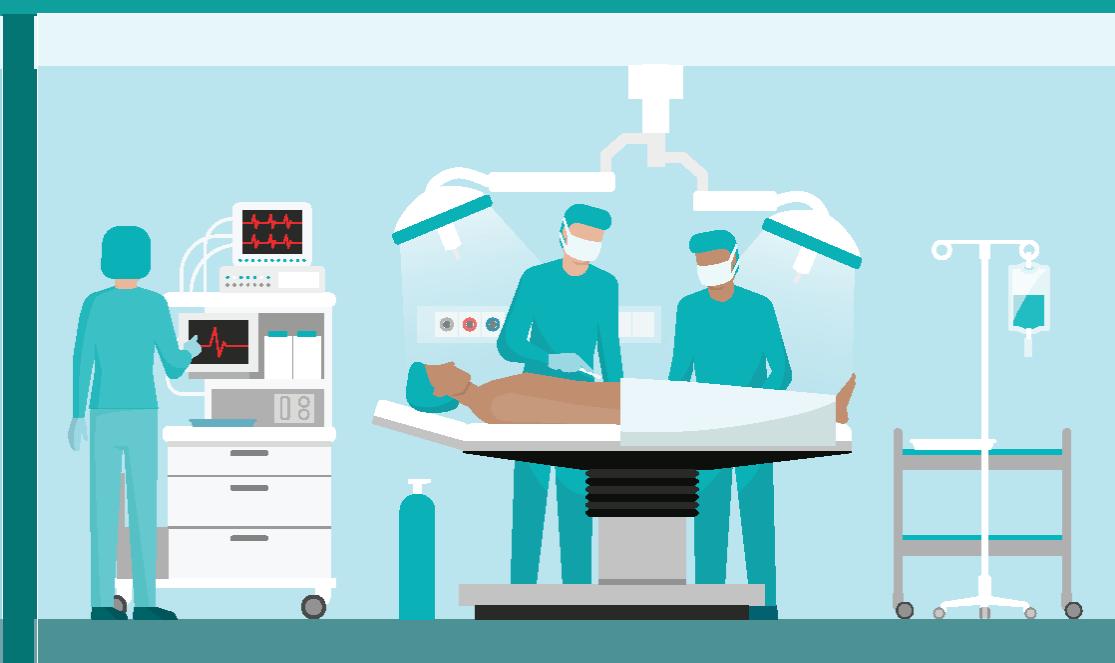
The rate of immunisation against various microbes is very poor in Argentina indicating a need for a highly comprehensive infection control initiative.

Initiative



Overview:

The Prevention and Infection Control unit at Hospital Universitario Austral aims to progressively and sustainably reduce the rate of infections associated with health care (HAI) by increasing adherence to effective preventive measures by staff, patients and their families. These measures cover all potential sources of infection within the hospital, including the hands of staff and family, medical devices or even accidental exposure.

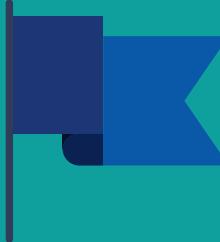




Some of the key aspects of the initiative:

- Ensuring effective surveillance of all patients across the departments with a specific focus on immunocompromised patients.
- Reporting signs of any infectious condition immediately upon recognition.
- Developing and implementing prevention measures for hand hygiene, such as by monitoring hand washing behaviour through the CCTV cameras and monitoring levels of alcohol hand wash consumption, and preventing transmission of microorganisms or infections from medical devices etc.
- Ensuring improved health of all the staff members by proving influenza vaccination for all and avoiding any infection through accidents.
- Conducting trainings for staff and educating patients, such as one-on-one meetings with patient and families prior to discharge to provide information on infection control.

Mission



Overview:

The Prevention and Control of Infections programme is specially designed and integrated with other programs and services of the organisation, to identify and systematically prevent potential transmission of infections among patients, visitors and health workers in a safe, high-quality and cost-effective manner.

Team



There is one doctor and three full-time nurses dedicated to infection control

The team hold a series of meetings to ensure effective adherence to measures. They have two meetings a week with the Quality Control team, one a month with the Infection Control Committee, and hold one-on-one sessions with medical teams as required, to provide and collect feedback on hygiene standards.

We want to continue to do more to capture and establish impact of our processes and share these, so other centres can learn from this as well.

Infection Control Team



Case study (cont.)

The programme has well defined goals for development, implementation and surveillance of protocols

There are five key components of the Prevention and Infection Control programme with specific goals and KPIs to effectively measure outcomes.



1

Surveillance system

Goals	Strategy/Initiatives	KPIs	Compliance
Consolidate the Vigilance System implemented with special focus on: <ul style="list-style-type: none"> — Infections in immunocompromised patients and Healthcare Associated Infections (HAI). — Report of notifiable infectious diseases. One specific objective is to achieve an annual rate of 11.4 HAI events per 1,000 patient days.	<ul style="list-style-type: none"> — Systematise HAI research in paediatric patients. — Develop and implement a process for the reporting of notifiable infections, coordinating the process of identification and reporting with the emergency area, outpatient clinics and laboratory. 	Expansion of the surveillance system.	<15 events with 1,000 patient-days

3

Prevention and Control of Infections in Health Personnel

Goal	Strategy/Initiatives	KPIs	Compliance
Prevention and Control of Infections in Health Personnel: <ul style="list-style-type: none"> — Immunoprophylaxis – achieve a 90% level of influenza vaccination among staff involved in care. — Prevention of accidental infection due to exposure to biological fluids. 	<ul style="list-style-type: none"> — Develop and implement a programme to ensure the level of immunological coverage of HVB, HVA, measles/rubella, tetanus/diphtheria/pertussis and varicella. — Articulate the process of information exchange with the Occupational Medicine Sector. 	Immunisation against influenza.	≥ 80% adherence to staff involved in care



Undertaking initiatives to ensure safe health of the staff as well as their training on maintaining quality are among key objectives of the program

2

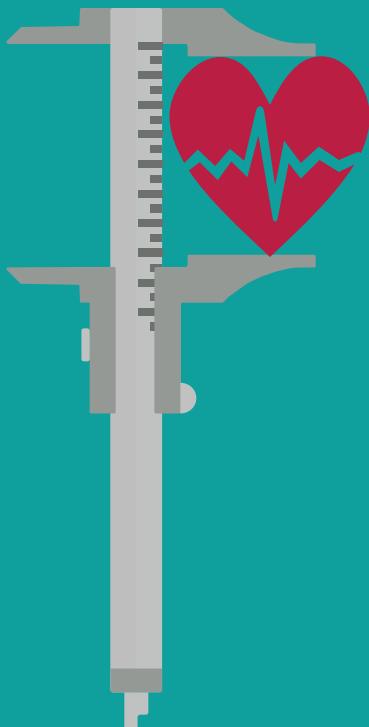
Development, review and implementation of standard protocols for prevention of infection

Goals	Strategy/Initiatives	KPIs	Compliance
Hand hygiene – achieving adherence to hand hygiene in all measurements at an institutional level, of not less than 80%.	<ul style="list-style-type: none">Ensure existence of resources necessary for hand hygiene (dispensers, sinks, alcohol-gel, neutral soap and paper towels).Hand hygiene compliance monitoring (cameras and hidden observers).	For surgical hand hygiene: <ul style="list-style-type: none">Consumption of resources provided.Availability of resources.	3 litres of surgical cleaning hand wash over 100 surgeries ≥ 90% compliance
Prevention and Control of infections associated with devices – e.g. mechanical ventilation-associated pneumonia is common in immunosuppressed patients.	Implement sector audits such: <ul style="list-style-type: none">Evaluation of the level of adherence of measures implemented with devolution by sector.Incidental assessment of the level of knowledge related to the policy of safe procedures.	Maintaining the rate of mechanical ventilation-associated pneumonia within NHSN system standards.	≤ 5.1 NAVM w/1,000 days-mechanical ventilation
Management of immunocompromised patients – Coordinate and standardise the identification system of high-risk individuals such as immunocompromised patients or those with transmissible infections.	<ul style="list-style-type: none">Develop and implement a programme to ensure the level of immunological coverage of HBV, HVA, measles/rubella, tetanus/diphtheria/pertussis and varicella.Articulate the process of information exchange with the Occupational Medicine Sector.	Immunisation against influenza for staff. Accidents due to exposure to biological fluids.	≥ 80% adherence to staff who interact with patients on a day-to-day basis <10 events with 10,000 patient days



Case study (cont.)

There are five key components of the Prevention and Infection Control programme with specific goals and KPIs to effectively measure outcomes (cont.)



Undertaking initiatives to ensure safe health of the staff as well as their training on maintaining quality are among key objectives of the program

4 Staff training

Goals	Strategy/Initiatives	KPIs	Compliance
Staff training – Implementation of an infection prevention control program.	— Develop and implement a training programme for all staff of the institution through formal induction, maintenance, athenaeums and incidental teaching meetings.	Training density	>90%
		Level of training acquired	>90%

5 Patient and family education

Goal	Strategy/Initiatives	KPIs	Compliance
Patient education	— Involve patients and families in the prevention of infections associated with health care.	Education imparted	>90%



The centre has been able to improve its outcomes such as demonstrating a reduced occurrence of infectious events associated with healthcare

Impact observed



Record of infectious events associated with health care has decreased by

35.5%

over 2015-16 y-o-y

Key learnings for replication:



- Align clinical and non-clinical staff on the need for infection control and prevention awareness and training; align on a consensus on the way forward, with a fully dedicated clinic.
- Provide training where specialist knowledge is required with these immunosuppressed patients (e.g. specialist immunologist nurses).
- Align on and implement a series of metrics for assessing impact of measures.
- Collaborate across institutes to share best practices and learnings.



Engaging with the healthcare environment

5





Building relationships with payers



What is the challenge?

Public and private Payers constitute a key stakeholder group in the provision of healthcare, and are responsible in large part for the variation in care delivery seen across the region. Payer policies have a direct impact across the entire patient pathway, whether this is coverage of diagnostics tests (e.g. IHC or FISH), medicines (e.g. targeted therapies), entire indications (e.g. limitations in coverage by Seguro Popular in Mexico) or areas of the patient journey (e.g. palliative care). Further, Payers may be wary of what they consider to be over-diagnosis or over zealous recommendations for medicines, and therefore be cautious in approving medicines that are off-label or not covered.

What is the initiative?



What have we observed?



Which patient is it for?

- All patients who may require access to a service (e.g. diagnostic tests such as genome sequencing) or medicine (e.g. targeted therapies) that are currently not covered by public or private Payers.

Which staff members are involved?

- Oncology/haematology physicians and administrative support teams.

What is offered as part of this initiative?

- A platform for generation of a scientific evidence base for reimbursement of off-label or advanced treatments.
- Establishment of long term relationships with the Payers:
 - Usually through a dedicated team within the centre.

What are the objectives?

- To build trust with Payers by only requesting reimbursement for scientifically proven and validated diagnostic or treatment paradigms.
- To improve access to services and medications for patients.

How was it achieved?

- Creation of a validated scientific evidence base, collected by a scientific review team:
 - Gathering evidence from guidelines, peer reviewed publications or conferences proceedings to build a case for treatment course;
 - Ensuring treatment course is reviewed and approved by a set of internal or external experts prior to engaging with Payers.

Implementation of dedicated teams:

- Training a dedicated team on reimbursement policies for various payers;
- Ensuring they act as part of the wider haematological malignancy care delivery team and empowering them to manage all relationships with the Payers.

What are the potential outcomes?



Clinical



- Improved diagnostics or prognostics.
- Improved clinical outcomes due to access to required testing/medicines.

Patient experience



- More accurate understanding of disease (e.g. due to prognostic data).
- Patient and family/carer satisfaction at gaining access to increased number of treatment options.



Selected case studies



Pre-Transplant Support Team – Hospital Universitario Austral, Argentina (see site visit report)

A dedicated team of two trained members to manage all aspects of reimbursement of treatments and medicines.



Scientific Advisory Board for Medicine Access – Americas Centro de Oncologia Integrado, Brazil (see site visit report)

A panel comprising experts from each haematological malignancy indication (e.g. CLL/CML) who are convened to discuss and validate proposed treatment courses prior to approaching Payers for reimbursement.

Additional options from other centres/global published literature



Engaging international experts to validate treatment (Hospital Universitario Austral, Argentina)

- Identifying and communicating with specific international experts to gain validation on certain treatment courses (e.g. off-label use) to add greater strength to request to Payers.

Working with Payers to enhance coverage (Instituto Nacional de Cancerología, Mexico)

- Developing the evidence base required (e.g. clinical outcomes, health economic analyses) to engage Payers and increase coverage of critical areas, such as specific indications.

Relationship with COFEPRIS (Hospital Ángele Lomas, Mexico)

- Access to very new medicines (e.g. recent FDA approvals) through rapid process. Within 24-48 hours a decision on drug availability is received.

Working with payers to increase coverage for 'best practice' or integrated patient management (Americas Centro de Oncología Integrado, Brazil)^(1, 2)

- Developing consensus on 'best practice' in care pathways between leading hospitals to engage Payers for improved reimbursement.

Supporting evidence from literature



- [Dawn Holcombe, Oncology Management Programs for Payers and Physicians: Evaluating Current Models and Diagnosing Successful Strategies for Payers and Physicians, 2011](#)
- [Blase N. Polite et al., Oncology Pathways—Preventing a Good Idea From Going Bad, Mar 2016](#)



Standardising protocols across all processes



What is the challenge?

International guidelines (e.g. NCCN from the USA or ESMO from Europe) are available and are regularly updated to reflect the most up to date thinking on the management of haematological malignancies. However, variation in healthcare coverage, particularly in access and availability of diagnostic/prognostic techniques and medicines, mean these need to be adapted to suit the national requirements in Latin America. Further, while population within some Latin American countries can be considered similar to Caucasian populations (where many guidelines are based), adaptation based on analysis of impact on local populations (e.g. local subpopulations, indigenous communities) can improve clinical outcomes and reduce the overall burden of disease.

What is the initiative?



What have we observed?



Which patient is it for?

- All patients.

Which staff members are involved?

- Mainly haemato-oncologists.

What is offered as part of this initiative?

- Adapting international guidelines to be more relevant within the national healthcare system
- Standardising treatment protocols to improve consistent delivery of care.

What are the objectives?

- To ensure guidelines followed are relevant, taking into account approved medicines, coverage considerations and local population genetic factors.
- To deliver a consistent standard of care across multiple hospitals.

How was it achieved?

- Adapting international guidelines to the national healthcare context and their dissemination:
 - Reviewing international guidelines, and adapting key aspects to suit the local environment;
 - Establishing consensus, and publishing these for access by the wider healthcare community within Latin America (e.g. through web pages).

- Establishing good practice in delivery of treatment protocols
 - Convening haemato-oncology specialists from across the country to discuss good practice in protocol delivery;
 - Agree and establish guidelines for standardisation of protocols and the delivery of care.

What are the potential outcomes?



Clinical

- More consistent clinical outcomes due to use of standardised protocols and methods of care delivery.

Patient experience

- Improved expectation management.
- Ability to receive consistent care across different centres.



Selected case studies



'Best practice' network for oncology – Americas Centro de Oncología Integrado, Brazil (see site visit report)

Convenes experts from across Brazil to discuss good practice in treatment protocols and develops consensus on care delivery.



Guideline adaptation and publication – Instituto Nacional de Cancerología, Mexico (see site visit report)

Works with government bodies to adapt international guidelines to the national environment, and publishes these online for use by centres throughout Mexico.

Additional options from other centres/global published literature



Working with international organisations for consensus guideline adaptation (National Comprehensive Cancer Network (NCCN) guidelines)⁽¹⁾

- Collaborating with organisations such as the National Comprehensive Cancer Network to adapt and publish guidelines for the Latin America region. Only selected haematological malignancy pathologies are currently available (e.g. multiple myeloma).

Using highly-specialised treatment algorithms (e.g. use of molecular profiling)⁽²⁾

- Specified criteria for developing treatment algorithms for personalised medicine, such as defining technology to be used, specifying threshold levels and quality control.

Publication of guidelines (freely accessible) (MD Anderson Cancer Centre, USA)⁽³⁾

- MD Anderson Cancer centre routinely publishes protocols for specific aspects of clinical management (e.g. management of neutropenic fever in haematological malignancy patients).

Supporting evidence from literature



- [International Adaptations & Translations of the NCCN Clinical Practice Guidelines in Oncology](#)
- [Christophe Le Tourneau et al., Treatment Algorithms Based on Tumor Molecular Profiling: The Essence of Precision Medicine Trials, 2016](#)
- [MD Anderson Cancer Centre, Neutropenic Fever Inpatient Adult Treatment \(Hematologic Cancers\), 2017](#)



Contributing to research



What is the challenge?

Haematological malignancies constitute a highly complex set of conditions, that require specialist knowledge for optimal management. Physicians must continue to build their knowledge, ensuring their knowledge and understanding is up to date with the latest scientific findings. This requires access to medical journals, congresses and the availability of collaborations and funding to undertake own research. Further, despite the high prevalence of haematological malignancies within the region, Latin America continues to lag behind USA and Europe in terms of its contribution to research, with a large variation seen across the countries (see literature review for reference).

What is the initiative?



Which patient is it for?

- All patients.

Which staff members are involved?

- Mainly physicians (haemato-oncologists, internal medicine specialists, radiotherapist and surgeons).

What is offered as part of this initiative?

- Dedicating time for production of research:
 - Building and maintaining databases;
 - Regular publication and dissemination of scientific research.

What have we observed?



What are the objectives?

- To contribute towards the progress of scientific research in haematological malignancies.
- To enable physicians to pursue a passion.
- To enhance the reputation of the centre.

How was it achieved?

- Implementing and maintaining databases of clinical and patient reported outcomes within the hospital. This is usually managed by a dedicated individual or team. The availability of Electronic Medical Records is critical for ease and accuracy of collating patient data.
- Empowering physicians to research an area of interest/passion.
- Dedicating time (e.g. a day per week to work from home on research, and providing required funding to enable regular production of research material).

What are the potential outcomes?



Clinical



- Improved clinical outcomes due to better understanding of patient population.
- Better patient management from greater understanding of latest thinking and good practice.



Patient experience



- Greater job satisfaction at being able to pursue an area of personal interest.
- Enhanced reputation for the individual and the centre.



Selected case studies



Haemato-oncology research unit – Hospital Universitario Austral, Argentina (see site visit report)

The haematological malignancy team are given a day per week to work from home focusing on a research topic of interest. This contributes to a high level of research production from the centre, as well as increase physician job satisfaction and work-life balance.



Dedicated data managers - ICESP, Brazil (see site visit report)

Staff within the haematology department are given defined roles for managing data collection to ensure that patient's data is effectively captured.



The staff are able to follow their passion and do something they really enjoy. We are given a day per week to focus on this, which is really unusual in a hospital setting.

Haemato-oncologist, Hospital Austral, Argentina

Additional options from other centres/global published literature



Dedicated research centre (Americas Centro de Oncologia Integrado site visit, Brazil)⁽¹⁾

- The Americas Centro de Oncologia Integrado (COI) Research Institute is a dedicated unit for the production of scientific and clinical research. All COI hospitals collaborate with the Institute, providing patient and clinical data. The developed and publication of research is driven by a dedicated team within the institute, which minimises time commitment required by the physicians.

Supporting evidence from literature



1. [Acevedo AM, Gomez A et al., Distribution and trends of hematology and oncology research in Latin America: A decade of uncertainty, Cancer. 2014 Apr 15;120\(8\):1237-45.](https://doi.org/10.1002/cncr.29137)



Exploring novel routes to access funding



What is the challenge?

Funding is a critical barrier in implementing effective haematological malignancy care across Latin America. Access to funding for the disease area is differentiated across the different countries. Funding is essential in ensuring the right equipment and facilities are available for the centres.

What is the initiative?



Which patient is it for?

- All patients.

Which staff members are involved?

- All physicians are required to help raise awareness but predominantly centre heads and administrative teams will be the key stakeholders involved in seeking out, engaging with and securing new sources of funding to support delivery of good practice care to patients with haematological malignancies.

What is offered as part of this initiative?

- Dedicating time for lobbying/policy creations/research.
- Dedicated time and resources for fundraising activities.
- Dedicated roles to bring new capabilities into the hospital/centre, e.g.
 - Focused role on handling contracting processes between entities;
 - Focused role on identification of novel sources of funding.

What are the potential outcomes?



Clinical

- Improved clinical outcomes due to better facility provision.
- Better patient management and care due to increased staffing.



Patient experience

- Greater access to a range of treatments.
- Enhanced reputation for the individual and the centre.





Where have we seen this?



Establishment of fundraising events – Fundaleu, Argentina (see site visit report)

Hosted fundraising events on a regular basis such as dinners. Places at such events were ticketed.



Public-Private-Partnership engagement – Hospital Regional de Alta Especialidad de Ixtapaluca, Mexico (see site visit report)

Engaged with PPP arrangements covering the procurement and maintenance of hospital building and facilities.

Additional options from other centres/global published literature



Equipment finance options for healthcare providers⁽¹⁾

- Hospitals can manage funding for latest technologies by forming joint ventures with other centres, and then applying for leases and loans.

Financing strategies for hospitals⁽²⁾

- Hospitals can undertake multiple strategies based on their own financial position and targets such as partnership with broad strategic capital options, capital markets etc.

Supporting evidence from literature



1. Hospitals can manage funding for latest technologies by forming joint ventures with other centres, and then applying for lease and loans.
2. Hospitals can undertake multiple strategies based on their own financial position and targets such as partnership with broad strategic capital options, capital markets etc.



Development of initiative platforms

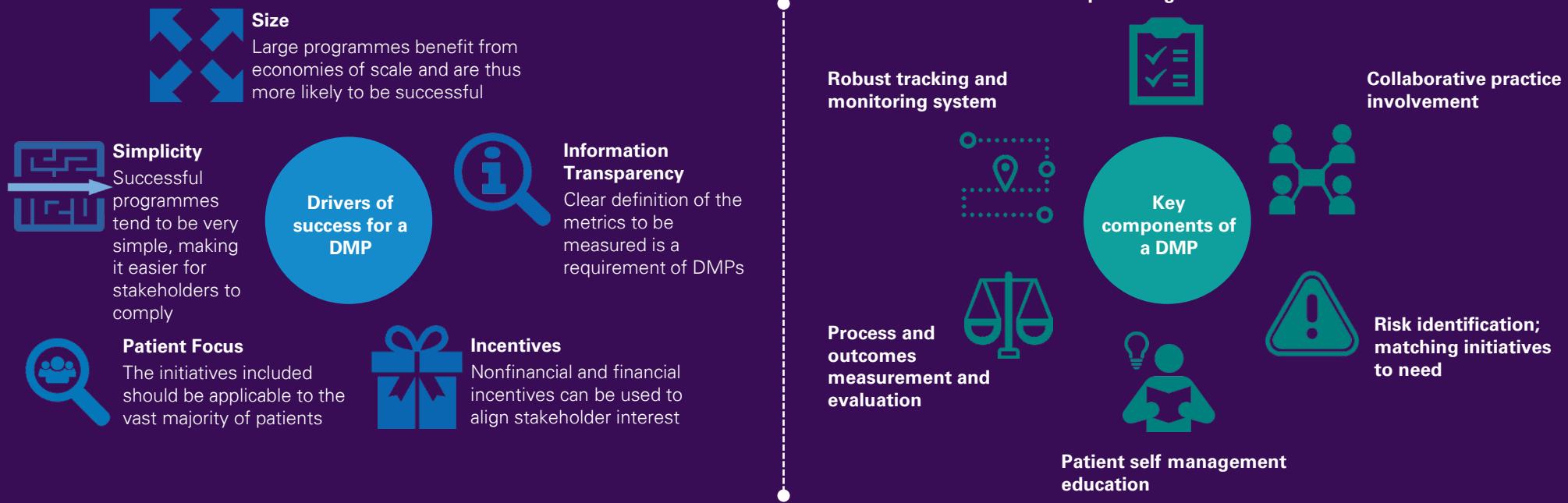
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If considered collectively, these initiatives could represent the basis for a Disease Management Programme for haematological malignancy



A Disease Management Programme (DMP) is a system of coordinated healthcare initiatives for a specific patient population, in which both healthcare providers and patients are empowered to manage the disease and prevent complications.



This report does not seek to develop a complete disease management programme for haematological malignancy, however identified good practice initiatives identified here **can form the basis upon which a Disease Management Programme for haematological malignancy could be developed for Latin America.**

Sources: (1) How to design a successful disease management program, S. Brandt 2010; (2) Concept series paper on Disease Management, Academy of Managed care Pharmacy;



Disease management programmes have emerged as an effective strategy in enhancing the quality of care received by patients suffering from chronic conditions



Chronic conditions are causing substantial economic pressures on healthcare systems. Patients whose conditions are not well-managed often experience costly and dangerous complications as well as hospitalisations that could have been avoided.

In haematological malignancies patients see many physicians across a variety of settings across the treatment pathway. Due to the lack of consistency of the guidelines and protocols to adhere to in Latin America, there is little coordination and continuity of care across service settings. Many patients fall into gaps along the treatment pathway, and this is exacerbated by lack of incentive, funding and support to help facilitate this care across these service settings.



Disease Management Programmes help to define and maximise the functionality and quality of patient care system and improve patient outcomes. This can help to reduce the increasing costs of chronic diseases on the healthcare system, ironing out inefficiencies of fragmented care, to help reduce adverse health outcomes.

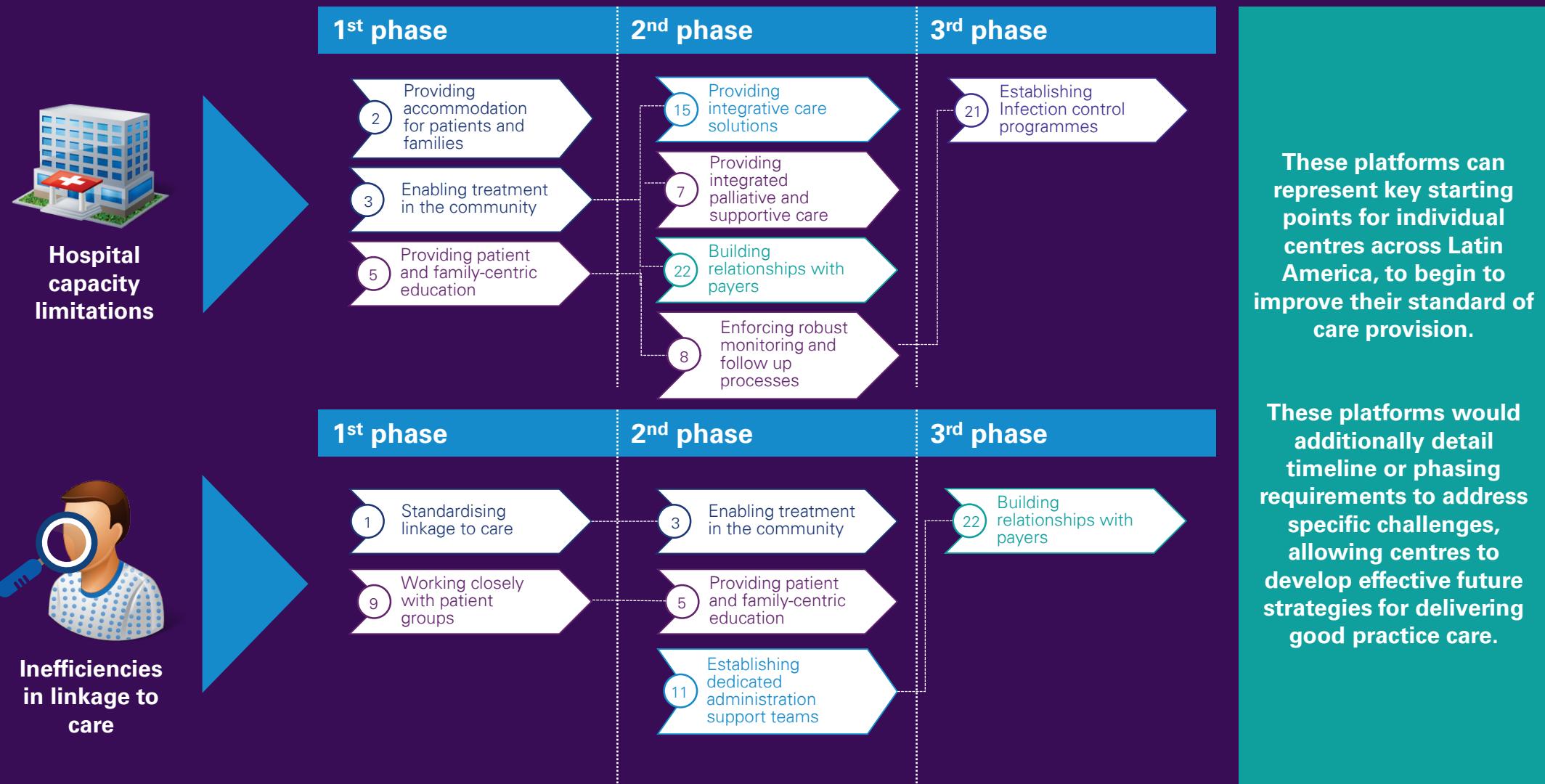


The patients receive a standardised, coordinated set of evidence-based interventions whose goals are to enhance the patients' health and quality of life, reduce the need for hospitalisation and other costly treatments, and thereby lower health care spending. Ideally, the savings obtained should exceed the programs' cost.



Sources: (1) D. P. Faxon et al. Improving Quality of Care Through Disease Management 2004;109:2651-2654, (2) S. Brandt et al. How to design a successful disease-management program. McKinsey, Oct 2010/<https://www.mckinsey.com/industries/healthcare-systems-and-services/our-insights/how-to-design-a-successful-disease-management-program>

Initiative platforms, based on synergies and dependencies between initiatives, can be developed to address key challenges for centres



Case study:



Germany's Disease Management Programme for Diabetes Type 2



In 2002 a series of DMPs were introduced nationwide in Germany in an effort to improve the quality and cost-effectiveness of health care for in a number of chronic disease areas. The first of these programmes was designed for type 2 diabetes, which has effectively demonstrated improvements in healthcare delivery, costs and patient satisfaction.

The DMP was rolled out amongst those patients covered statutory health insurance, covering 86% of the German population. Participation was voluntary for both physicians and patients, however financial incentives were provided companies in order to help promote integration, participation and the success of these programmes.

After 6 years of the launch of the DMP, around of the estimated 5 million insured patients with type 2 diabetes were enrolled in the program.

64%

The results have demonstrated significant patient benefits and outcomes. There has been a increase in patient satisfaction across the treatment pathway.

16%

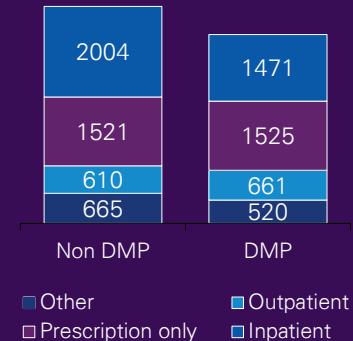
Overall cost of care in type 2 diabetes has been lowered by



"Patients are now significantly more likely to have their feet checked regularly by a specialist, as a result of which the incidence of certain types of foot ulcer has plummeted."

The small increases the program has produced in outpatient and pharmaceutical costs have been more than offset by a drop of more than 25% in inpatient costs.

Costs of care of patients with Type 2 Diabetes
€ per insured per year



Sources: (1) Busse R: Disease management programs in Germany's statutory health insurance system. Health Aff 2004; 23: 56- 67; (2) http://www.bundesversicherungsamt.de/cln_160/nn_1046648/DE/DMP/dmp_node.html?__nnn=true;



8. Appendix





8i. Centre-specific findings



Hospital Universitario Austral

Department of Haematology

Buenos Aires, Argentina

—

KPMG, June 2017





A highly patient centric care pathways is a key feature of Hospital Universitario Austral

Key findings from the centre



Top-down focus on patient safety and quality

- Multiple internal initiatives that highlight the importance of patient safety for all healthcare workers; with 'safety' being seen as a philosophy, prioritised and driven top-down from hospital management. Dedicated quality control team with sophisticated database that captures multiple clinical outcomes, (e.g. time for re-admission post-discharge, rate of post transfusion fever etc.

Close-knit teams working in a highly-collaborative manner across departments

- Highly-collaborative MDT approach to patient care, with haematology and internal medicine teams conducting ward rounds together; regular MDT meetings to discuss and agree on treatment plans.

Strong BMT unit providing high-quality patient care

- Provides autologous, allogenic (haploidentical and unrelated) and cord blood transplants; these are harvested under anaesthesia or through leukapheresis. Patient management is through a dedicated unit, providing holistic medical, complimentary and administrative support to patients.

Open and frequent patient communication to build trust

- HCPs enter into an 'informal contract' with patients discussing in great length the team, what treatment is going to be deployed, what we know, what guidelines are used etc. to try and develop their trust in the team.

Key challenges faced in the delivery of haematological malignancy care



Limited awareness of the need for blood/bone marrow donors

- Although the hospital has a steady donor base, there is limited or no awareness within the community of the need to donate blood or bone marrow, which may lead to delays in treatments.

Difficulties in ensuring safety post-transplant in highly heterogeneous income patient pool

- The centre treats patients from across Argentina, some of whom may not have adequate housing/facilities which are required to be eligible for bone marrow transplants.

Funding and access to treatments

- Funding of treatments, especially for patients from outside Buenos Aires continues to be a key issue. Centre works with foundations from Venezuela, Peru, Bolivia and Ecuador. The high price of new cancer therapies, especially the biologics, make it very difficult to manage costs.



It is a well-accredited centre treating haematological malignancy patients from across the region

Haematological malignancy specialty unit



Services: JCI-accredited. In - and out - patient care of paediatric and adult patients with advanced or relapsed haematological malignancies. Specialised Bone Marrow Transplant unit.

Resources: One building located in Pilar, comprising medical and transplant unit, diagnostics, central labs, cell processing unit/blood bank.

Teaching: Multiple training programmes, in collaboration with Universitario Austral. Includes rotational programmes from haematology trainees from across Latin America.

Collaborations: Industry collaborations for limited clinical trials; close collaborations with University Austral including Centre for Translational Medicine.

Funding: Opus Dei funded; additional ad hoc collaborations with NGOs that provide funding for individual patient care.

Haematologist(s): Five haemato-oncologists.

The patients

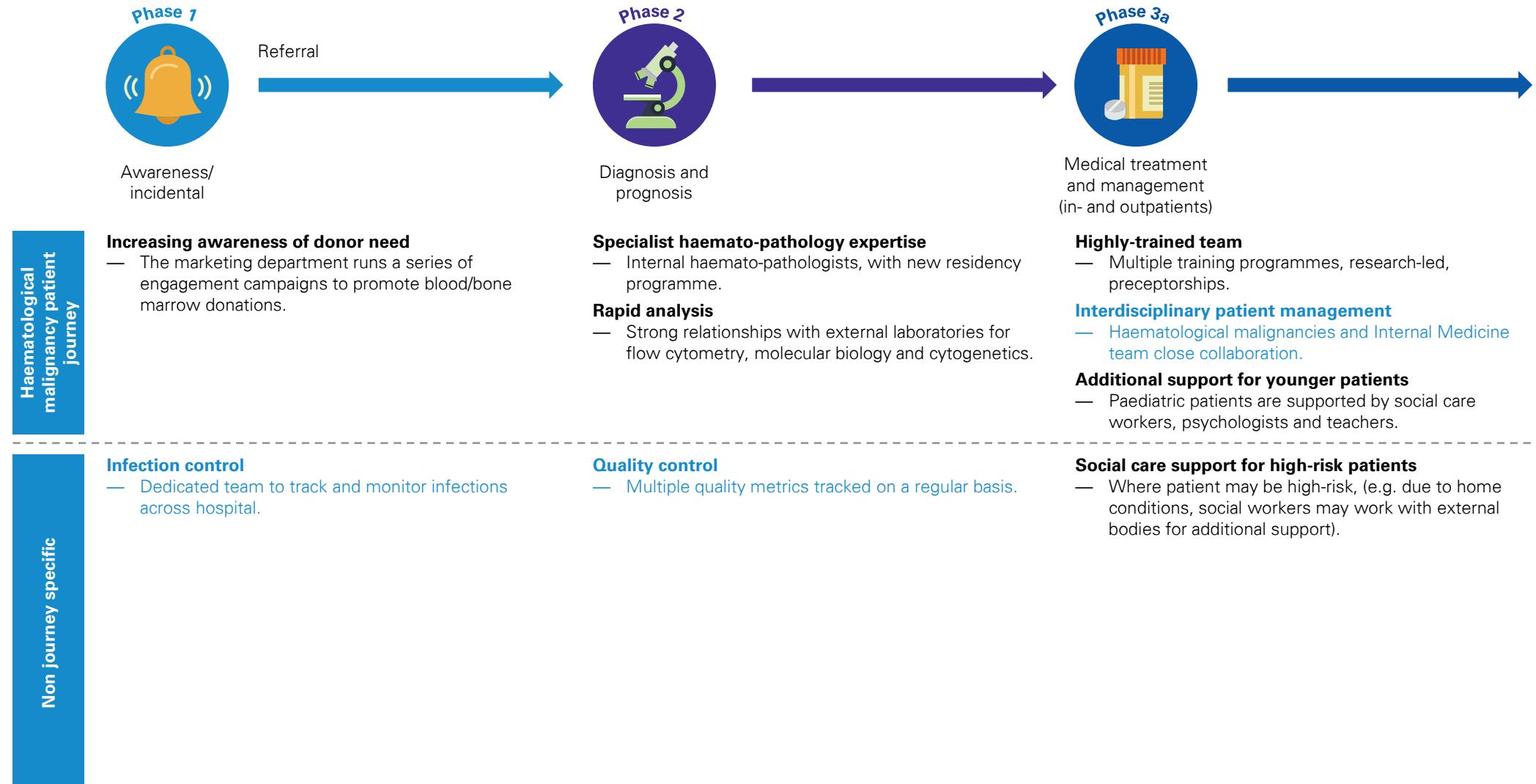


Geographic scope: Referred paediatric and adult patients from across Argentina and Latin America.

Patient population: Paediatric and adult patients from across Argentina and other Latin American countries, inc. Venezuela, Bolivia, Peru and Ecuador.



There are a number of specific initiatives in place to ensure patient support





Phase 3b
Bone marrow transplantation



Phase 3c
Monitoring and follow-up



Phase 4
Palliative care

Blue text = Case study available

Pre-transplant support team

- Team to support all admin tasks related to BMT.

Social care support

- One-hour consultation with all patients eligible for transplant.

Mobile filters to increase capacity

- Two permanent rooms and two more that can be transformed.

Haemato-oncology research unit

- One day per week to focus on a research project of interest.

Patient education

- Patient education programme which begins prior to admission and is maintained regularly through discharge.

Patient signposting

- Page on door of each patient outlining key safety aspects.

In-hospital treatment

- Dedicated palliative care unit to support patients and families.

Patient trust - informal contract

- A number of initiatives to develop and maintain the patient's trust.



The centre has a highly collaborative team that closely monitor the patient

Key features of the haematological malignancy care delivery team:



- Multidisciplinary management of patients, with regular team involving haematologists, nurses, pharmacists, psychologists.
- Highly collaborative team working across specialities, (e.g. Internal Medicine and Haemato-oncology conduct ward rounds together).
- Pre-transplant support team which builds close relationship with patients, meeting them on their first appointment, supporting with administrative tasks related to funding and maintaining regular contact.
- Specialised nursing team who work closely with patients, spending time to educate patients and their carers before and after procedures.
- Regular meetings with infection control teams, (e.g. one on one feedback on hygiene/monthly morbidity and mortality meetings).
- Social worker has one hour meeting with all transplant patients to assess readiness.
- Strong emphasis on well-being of medical staff, with flexible hours, and ability to work from home (e.g. for research).

Governance and processes



Team meetings:

One MDT meeting a week; one haematology team meeting a week, two team 'away days' a year (to plan the future of unit).

Patient records:

All medical records on electronic system, with access for medical staff, payers and patients. No paper used in hospital except in the pharmacy.

Pharmacy:

Depending on funding system, patient may bring own medicine to pharmacy.



For us it is about having patient safety and quality of care at the forefront of everything we do. But it is also about ensuring HCP satisfaction. We have a very good, very human team that I am very proud to work with

This is not a symmetric relationship. I wanted to be here, I trained for it. The patient never wanted to be in their position. So no one can mistreat a patient. We need to make sure we give the same support to all the patients.

Head, Haemato-oncology





How can haematological malignancies care be improved?

What is next for the centre?



Greater outpatient facilities for chemotherapy

Current space for outpatients is limited, especially due to increased demand. There is room for growth, including creation of a separate outpatient unit for immuno-suppressed patients.

Improved diagnostic capabilities in-house

While current diagnostics are strong, this can be improved by addition of in-house molecular diagnostics/flow cytometry and gene sequencing capabilities. Currently these are conducted externally, with good timelines for results.

What advice would you give to less specialised centres?



Build patients' trust Invest time in getting to know the patients, their personal situations and requirements. This enables trust to be built between physicians and their patients and provides sufficient support to ensure they are able to adhere to the treatment recommended.

Ensure patient safety Simple initiatives, such as notices on doors, can ensure patients at risk (e.g. from falls/immunocompromised) are given special attention.

Look after the medical team Ensuring the mental and physical well-being of the medical team (doctors, nurses etc.) is critical to a high-functioning delivery team. This can be supported through the promotion of collaboration and flexibility for these physicians.



Case studies



Interdisciplinary patient management



Overview

Close collaboration between haemato-oncology and internal medicine teams to ensure better patient management.

What is the rationale?



Closer collaboration between the two specialties ensures better patient management and continuity of care, as well as better specialist training.

What are the key features of the initiative?



Haemato-oncology and internal medicine teams collaborate very closely together – this includes conducting ward rounds together (both specialists and residents).

Any modifications required to the treatments are made through decisions taken together, and any medical records are updated at the same time. This is also a good way of building patients' trust in the treatment protocol and the HCPs they see.

As most of the residents are also trained at Austral, they have a strong sense of the culture and philosophy of the hospital, but this process helps to support and strengthen this even more.

What is the additional staffing requirement?



No additional resource requirement; greater time management and collaboration required to ensure ward rounds/discussions are done together.

What are the challenges faced by the initiative?



Changing mind-set/siloed behaviour of different specialities. This has been overcome by like-minded individuals who all believe in the culture and philosophy of the hospital, and understand the importance of close collaboration for better patient care.

What is the impact?



The team believe the impacts are:

- Patients are safer.
- Better care is provided at all times.
- Greater trust is generated from the patients as they see close collaboration and continuity of care.

What are the challenges of replicating this?



Changing mind-set of care practitioners to help reduce siloed behaviour.
Logistics required for conducting ward rounds/meetings at the same time.



Haem-onc and internal medicine working together like this is very unusual as its not often done so closely together in other hospitals.



Internal Medicine



Pre-transplant support team



Overview

A dedicated two-person team to manage all admin aspects of patients, including hospital navigation, dealing with payers, co-ordination of approval of chemotherapy drugs, engaging with blood/donor banks, and liaising with social care workers to ensure adequate safety and support.

What is the rationale?



The management of all the bureaucracy that surrounds a patient undergoing BMT is often the responsibility of the medical team or patients. This a significant burden on the time of both parties. A dedicated team to manage all administrative tasks is seen as a huge differentiator in patient care.

What are the key features of the initiative?



A dedicated team of two, whose responsibilities include (but are not limited to): liaising with CUCAI in search for donors, contact with other registries/Anthony Nolan centre for donors, logistics of transport to the hospital, working with social care, unions, payers etc. to make sure all paperwork is done and approval for treatments/chemotherapy is gained.

A key aspect of the role is managing timelines and patient expectations. This is done through building a strong and trusting relationship right from the start so the patient is happy to discuss and trust the information that is being shared. One of the team will meet patients at the reception when they first arrive and have a chat with the patient that is not related to their diagnosis, but to get to know them on a personal level, such as nicknames, marital status, children, pets, soccer team, and continue to have close contact with family over the duration of the patient's stay in the hospital.

What is the additional staffing requirement?



Two people, full-time. Training provided on-the-job by haematological malignancy delivery team.

What are the challenges faced by the initiative?



Managing patient expectations is a key challenge, which is addressed by building a strong relationship right from the start so the patient is happy to trust the information and guidance provided by the team.

What is the impact?



The impact of this service on patient experience has been significant, and patients always refer to this when they are leaving the hospital and are appreciative of the support they receive. Recognising this, the Natalie Dafne Flexer Foundation, an Argentine foundation for children with cancer, have invited one of the team members to give a talk on his role and how they work with patients.

What are the challenges of replicating this?



Approval for the provision of this service from the hospital administration.

Training for the team members; and close collaboration with the haematological malignancies delivery team to ensure shared vision and philosophy.



We want the patient to forget completely about the admin side of things, and leave all bureaucracy to us.



Pre-Transplant Team



Infection control



Overview

A dedicated infection control team who educate, monitor and ensure infection control across the hospital, contributing to high-level patient safety.

What is the rationale?



Infection control is of critical importance throughout the hospital, but especially a concern within the haematological malignancy unit due to the immunocompromised nature of many patients. The dedicated team which monitor hand hygiene and general cleanliness has resulted in a strong impact on infection rates across the hospital.

What are the key features of the initiative?



The hospital monitors the hand hygiene of all medical staff: reports are provided on hand hygiene through observations near hand washing stations. This entails the monitoring of hand washing behaviour through the CCTV cameras and monitoring levels of alcohol hand wash consumption.

Ensuring that bed cleanliness is maintained, through provision of education for cleaning staff and regular monitoring of bed conditions.

Providing education to patients and their families about infection control and prevention through one-on-one meetings prior to patient discharge (e.g. how to prevent infection through catheters).

The team hold meetings once a month with the Infection Control committee, two per week with Quality Control and one-on-one sessions with medical teams as required to provide feedback on hygiene standards.



We want to continue to do more to capture and establish impact of our processes and share these, so other centres can learn from this as well.

 Infection Control Nurse





Quality control



Overview

Hospital wide system for monitoring multiple quality metrics, that are reviewed at monthly meetings and used to improve patient and HCP experience and ensuring quality control.

What is the rationale?



Safety and quality of patient care are central to Hospital Austral, and a dedicated team focused on this task enables transparency and consistency in how the data is collected and analysed.

What are the key features of the initiative?



A dedicated team that track multiple quality metrics across the hospital. It is the responsibility of the HCPs to report any incident that may impact quality, (e.g. broken equipment/patient falls).

Example data collected includes: rate of return to hospital within 30-days post transplant due to complications, such as fever; re-entrance after discharge (general); DVT prevention guidelines (prophylaxis treatments given); thrombosis/thromboembolism incidence; glucose/glycaemia management; security reports (e.g. incomplete names on medical records, incorrect fluids, falls, patient not well educated); neutropenic fever (treatment, time, patient mortality).

What is the additional staffing requirement?



Five people (doctors and nurses); all part time.

What are the challenges faced by the initiative?



Changing mind-set about reporting quality metrics; ensuring it is not seen as a requirement that simply uses up extra time. Addressed by making the results of the metrics visible and that the impact it has on the hospital is clear through good communication. It is now not seen as a burden by doctors but a routine of their job .

What is the impact?



The team have been able to demonstrate consistent reduction/maintenance of multiple quality metrics that are tracked. These are shared at the monthly morbidity/mortality meetings where any decisions to be made to improve patient/HCP care is discussed.

What are the challenges of replicating this?



The cost of a dedicated team.

Changing the mind-set and reducing the resistance from hospital to regularly capturing quality data.

Effective means of communicating impact of data capture.



We are aiming to get the job well done each time. I am very happy to be a part of this culture and strongly believe in its worth and the impact it has on the hospital, patients and healthcare workers.



Quality control doctor

Haemato-oncology research unit



Overview

The haemato-oncology team is given one day per week to work on own research, thereby contributing a high level of production of research from the unit, and enabling the team to focus on a topic they are passionate about.

What is the rationale?



Ensuring an engaged, and forward thinking haematological malignancy delivery team is critical for high-quality patient care. Contribution to research is seen as a critical aspect of this by the haematological malignancy unit within Austral.

What are the key features of the initiative?



The medical team is able to work from home one day per week; to focus on research. The team is able to select topics of interest to themselves, as well as leverage any collaborations/relationships they hold with external organisations.

The topics of research are wide ranging, however particular attention is paid to reducing the number of deaths from transplant. Other key activities include close collaboration with GATMO (Argentine Group of Bone Marrow Transplantation) to improve access to INCUCAI (National Registry of CPH Donors). This is one more reason for conducting more detailed retrospective analyses from across the region.

What is the additional staffing requirement?



One day per week for haemato-oncologists work from home, focusing on research.

What are the challenges faced by the initiative?



Ensuring topics of interest to each of the medical team is given an opportunity. This is addressed by working in a very collaborative manner; anyone with a good idea is able to come forward and gain support.

What is the impact?



This initiative has provided the team an opportunity to follow special interests, contribute to science, develop better ideas of how to improve patient management and predict and mitigate risks.

It has also led to increased visibility of the centre, and thereby an increase in referrals.

What are the challenges of replicating this?



The logistics of ensuring dedicated time for research.

Time and financial commitments required for publications.

Management of clinical and research aspects of patient care.



The staff are able to follow their passions and do something they really enjoy. We are given a day a week to focus on this, which is really unusual in a hospital setting.

 **Haemato-oncologist**



Patient signposting



Overview

Key patient information is listed on a poster on the front of the door of their room to ensure correct recognition of the patients and the correct treatment catering for their personal requirements.

What is the rationale?



The correct identification of patients remains key in ensuring patient safety. A simple solution to supporting this is providing a clear overview of patient status (e.g. risk level, allergies etc.) as a sign post.

What are the key features of the initiative?



A signpost on the door of each patient, outlining key aspects of the patient that a HCP would need to know to correctly identify and maximise safety, e.g.:

- Name/commonly used name;
- If there is another patient with a similar name in the ward;
- Risks – greater susceptibility to fall/allergies/ulcers;
- Neutropenia.

What is the additional staffing requirement?



Minimal, nurse to review and update signposting.

What are the challenges faced by the initiative?



No challenges currently. In the past falls were unreported, but now are closely monitored.

What is the impact?



This initiative, together with training of staff/close monitoring of quality metrics across the hospital, is believed to have led to improved patient safety.

What are the challenges of replicating this?



Agreeing key information required to be displayed.

Implementing the initiative systematically across wards.

Capturing the impact of the initiative (e.g. patient surveys/data).



In the past we did not closely monitor falls, but now it is closely monitored!



Nurse



Patient trust – informal contracts



Overview

Building patients' trust in the hospital physicians remains a key aspect of developing strong relationships. A number of activities, including patient trust charters, clear communication, planned patient education sessions and collateral can be used.

What is the rationale?



Gaining and maintaining the trust of the patient is critical to the delivery of good quality care. This is particularly true in haematological malignancies, which are often chronic.

What are the key features of the initiative?



The haematological malignancy care delivery team enter into 'informal contracts' with the aim of building a strong trusting relationship with their patients; which is supported by a number of initiatives:

- Conversation with the patient at a 'personal' level, i.e. to find details of nicknames/pets/children/soccer team they support etc. by the Pre-Transplant Support Team.
- Open communication with the patient to explain diagnosis, protocols, current understanding by the physicians.
- Patient education programme run by nurses, that begins prior to admission and continuous throughout their stay until discharge.
- Clearly displayed notices throughout the hospital that describe patient rights/commitment to patients.

What is the additional staffing requirement?



Minimal, agreement on common way of working and developing required collateral, such as education brochures.

What are the challenges faced by the initiative?



Ensuring all the haematological malignancy care delivery team have the same approach and attitude towards building and maintaining patient relationships. As most of the residents/nurses are trained at the hospital, this is instilled in the team from an early stage.

What is the impact?



Strong relationships with patients with the ability to resolve most aspects of patient care. Anecdotal feedback on patient satisfaction with the hospital, however, plans must be in place to implement a survey to capture feedback.

What are the challenges of replicating this?



Top-down commitment to building and maintaining patient trust.

Training programmes to ensure all haematological malignancy care delivery team approach patient management in a similar manner.

Collateral support, (e.g. brochures/information booklets).



We know our patients leave very happy.

 Nurse



Fundación Para Combatir la Leucemia (Fundaleu)

Buenos Aires, Argentina

—
KPMG, June 2017





A collaborative, MDT approach to care is a key feature of Fundaleu

Key findings from the centre



Strong, interdependent teams working in a highly-collaborative manner across departments

- Highly-collaborative MDT approach to patient care, with meetings every morning providing integrated and informed care across the patient pathway. For example some sessions are endorsed with an academic review of papers, leading to team development and increasing patient support.

Strong emphasis on education and training

- They have a culture of training embedded into their centre, providing renowned workshops covering a variety of indications and subject areas; MM, CLL, Lymphoma, Myelodysplastic syndrome, CML and one focused specifically on laboratory diagnostic processes and techniques. These workshops are sponsored by industry players, who invite leading figures from across the world who specialise in a subject area to attend the workshop and speak. These workshops are well attended by physicians from all over Latin America, mainly specialists. Additionally, they provide training and services to the provinces of Argentina and other countries within the region who receive less funding.

Highly patient-centric care system

- Multiple internal initiatives that put patient centricity at the forefront of their care. These include bringing care to the patient such as ICU services, as well as providing holistic care across the patient pathway, such as integrative oncology services.

Key challenges faced in the delivery of haematological malignancy care



Variation in medicine regulation

- Variation in the regulation of how medicines are sourced both nationally and internationally means there are differences in quality. Additionally the national regulations leave too much decision of prescription to doctors, who do not assess the cost effectiveness of treatment to the system. Regulations need to be more clearly defined around the traceability and prescription of medicines in order to ensure practitioners and insurers abide by the same protocols.

Lack of specialist training programmes for haematological malignancies

- There are currently limited/no training programmes in place for certain haematological malignancies specialisms, such as dentists or nurses. They tend to learn on the job. This may be due to lack of awareness of the importance of role of nursing/dentists etc.. in management of haematological malignancy patients and the need for specialised training. Launch of systematic training programmes and evidence-based guidelines development for haematological malignancy clinical nursing/dentistry practices could support this.



It is a highly-specialised centre focused only on the treatment of haematological malignancies

Haematological malignancy specialty unit



Services:	Fundaleu structures its services under three pillars: patient care, clinical investigation and teaching; in- and out-patient care of paediatric; and adult patients with advanced or relapsed haematological malignancies.	Collaborations:	Industry collaborations for clinical trials; close collaborations with CEMIC (Sanger genetic sequencing techniques) and Infinicyt/EUROFLOW (FC database).
Resources:	Three buildings located within one block of each other, comprising inpatient, outpatient and labs for diagnosis.	Funding:	Privately funded, not-for-profit organisation. Strong reliance on fundraising, charitable donations and third party payers (health insurance – mostly private; social security; sponsorship from two-three foundations (e.g. Toshiba supplying equipment).
Teaching:	Launched its official teaching programme in 1997. Physicians trained in Fundaleu rotate out to remote regions/provinces. Since 2009, Fundaleu has been running a specialist haemato-pathology course.	Haematologist(s):	10 haematologist; One haematopathologist.

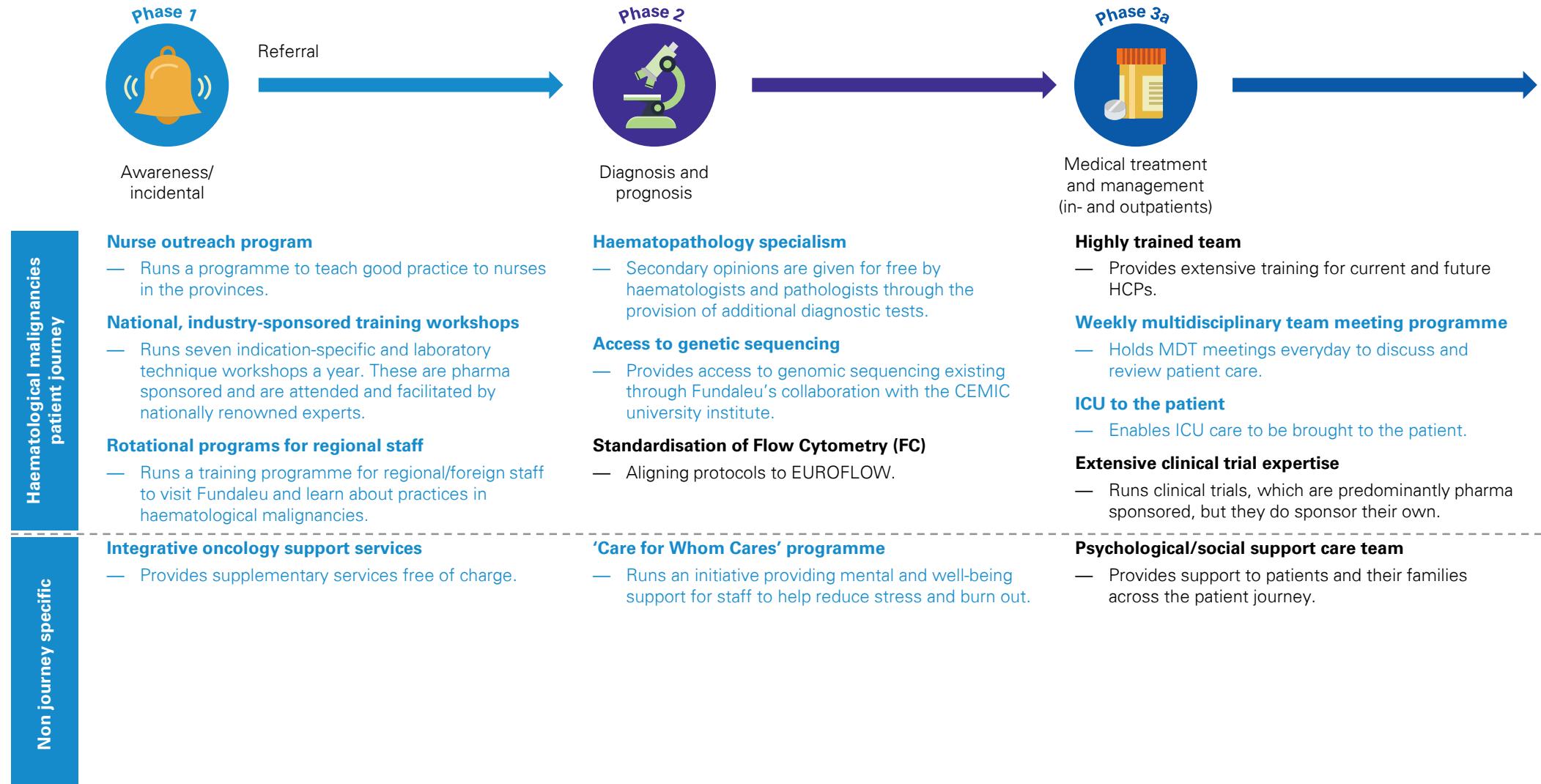
The patients



Geographic scope:	Patients come to Fundaleu from across Argentina and Latin America.
Patient population:	Referred patients (only adult and no paediatric) from secondary care setting. Most patients have received private healthcare.
Number of patients:	150 inpatients; 250 ambulatory patients; 2500 consultations per month.
Patients' characteristics:	Do not treat benign haematology issues (e.g. anaemias) unless secondary to haemato-oncology.



There are a very high number of specialised initiatives for patient support





Blue text = Case study available



Phase 3b
Bone marrow transplantation



Phase 3c
Monitoring and follow-up



Phase 4
Palliative care

Specific BMT secretary

- Employs a personalised BMT secretary to monitor all operations and follow-up appointment.

Haemato-oncology dentist

- Employs a specialist dentist who assesses all patients prior to BMT and monthly then six monthly check-ups.

Rapid access to donors

- Has rapid and extensive access to donors, with over 5,000 per year.

Quality control

- Ensures robust processes and services are in place to help maintain quality.

Patient education

- Ensures patient education is provided by nurses, and maintained regularly through the course of patient treatment and follow-up.

Specialised haemato-oncology imaging services

- Provides extensive access to facilities which can be used to track treatment success and disease progression and employs staff with specific haematology backgrounds/training.

Empowering families

- Allows and encourages families to be part of the treatment and management of their patient, whilst in hospital.

Specialist palliative care team

- Employs one part-time physician who works directly with nurses to provide end-of-life care. This is primarily funded by the Fundaleu foundation.

Patient centricity at the heart of values

- Staff are all very close to their patients being involved across the patients pathway.



Summary

The centre has different MDTs that specialise in various haematological malignancy pathologies

Key features of the haematological malignancy care delivery team:



- Most of the team are full-time employees of Fundaleu.
- All of the team demonstrate a haematology specialism (e.g. haemato-pathology, specialist dental support etc.).
- Different multidisciplinary team meetings occur daily, involving the full haematological malignancy care team and auxiliary members (e.g. social workers).
- ICU team brings intensive care to the patient and closely collaborates with the haematology team.
- Psychological support team is available to both patients and their families .
- Active nurse support across the patient journey, with each patient maintaining the same nurse throughout their care.
- Trained infection control nurse provides training for new nurses and the cleaning team in how to reduce infection risk.
- Integrative oncology support staff.
- Fundaleu offers a 360 degree emotional support for the patient and their family throughout the course of their disease.
- Fundaleu operates a 'Care for Whom Cares' scheme demonstrating a strong emphasis on well-being of medical and support staff.

Governance and processes



Team meetings:

There are eight different MDT meetings in place per week, providing both patient care review and academic development of staff.

Patient records:

Implemented an electronic medical record system (50% completed to date), with varying access for medical staff, payers and patients.

Pharmacy:

Due to established relationships with OSDE health insurance, specific expensive drugs are maintained on site, ensuring continuity of treatment.



We are probably the only specifically focused haemato-oncology centre in Latin America. We are very proud of the state-of-the-art care we offer here. Our patient outcomes are comparable to the best centres in the world.

Head, Haemato-oncology





How can haematological malignancies care be improved?

What is next for the centre?



Community care visits

Some patients require care within their home, due to issues of susceptibility to infection or immobility. Additionally, the outpatient system has high costs and there is increasing strain due to space and capacity.

Increasing infection control capabilities

While there is a strong infection control team there are only two to monitor both inpatients and outpatients with infectious diseases. There is a supportive nursing team however there is no specialist nurse in charge of infection control with full-time dedication, only one trained nurse is in charge of disseminating the training to all newer nurses. Hiring a additional specialist nurse(s) will reduce the burden, training and treatment load for Infectologist physicians. They could help to educate staff, and collaborate with nutritionists in educating patients to manage infection risk.

What advice would you give to less specialised centres?



Collaborative team working environment

Invest time into sharing patient information across all practitioners is inexpensive and key to making good decisions, leading to high patient satisfaction and better outcomes across the patient journey.

Bringing care to the patient

By keeping the patient in the same context for their care across the journey is key in increasing patient satisfaction, ensuring they keep the same relationships with staff, and preventing possibilities for infection.

Look after the medical team

Ensuring the mental and physical well-being of the medical team (doctors, nurses etc.) is critical to a high-functioning delivery team.



Case studies



Nursing outreach programme



Overview

The outreach programme is partnered with the Argentine Society of Haematology for Nurses, and has been developed for those who have a passion to teach. These nurses go out into the provinces to teach haemato-oncology nursing care to less well-resourced centres.

What is the rationale?



The head of the nursing department used to drive this initiative internally and independently, reaching out to the provinces herself. The Argentine Society learnt of this and developed a connection in order to help support this initiative and increase the reach of the programme to more provinces.

What are the key features of the initiative?



From 1997 there have been five-seven nurses a year enrolled in this programme travelling from Fundaleu to the provinces. These visits can be as short as one day or much longer. During their trips they will educate and train nurses in how to monitor and treat patients suffering from haematological malignancies.

Having partnered with the Argentine Society, the trips have expanded with a further reach. The programme is now open to other institutes to enrol, ensuring that nurses working across other centres in Argentina can take part in this initiative.

The Argentine society decides where to send the nurses in the program; destination is dependent on where the most care is needed.

In addition to this outreach program, Hospital Fundaleu has worked alongside Hospital Austral and the associated university to implement training workshops to help support and resource nurses effectively for these outreach trips. This is a one day training workshop and occurs once a year. Nurses getting their nursing license at Hospital Austral are obligated to work in Fundaleu as part of their training, strengthening the link between the two centres.

What is the additional staffing requirement?



Sufficient nursing staff to permit members to do work externally with regional centres. Funding to cover travel and accommodation during these visits.

What are the challenges faced by the initiative?



Funding for the expansion of the nursing outreach programme was initially a challenge. This was addressed by engaging the Argentine Society of Haematology, who now help to support Fundaleu by covering much of the costs. The Fundaleu Foundation covers remaining costs following the societies contribution.

What is the impact?



Regional centres can benefit from having nurses from leading centres come in and help train both their staff and review their current practices. Ultimately this serves to improve care provision and patient outcomes.

Because of the training partnership with Hospital Austral and the associated university, the Fundaleu Foundation now has strong relationships to which they can reach out on an ad hoc basis for training of nurses.

What are the challenges of replicating this?



An organisation has to have enough nursing staff to be able to send out.

Arranging travel and accommodation for nursing staff while visiting regional centres.



Nurses views on patient care is highly valued by other staff. Nurses are allowed to make proposals on how to improve care delivery.



Nurse



National, industry-sponsored training workshops



Overview

Specialist training workshops for individuals involved in the management of haematological malignancies across Argentina to help disseminate recent findings and educate on good practice care across different indications and processes.

What is the rationale?



This initiative provides a platform for leading physicians and diagnostic staff to share knowledge and improve the regional standard of care. The discussion of complex cases serves to widen the collective experience of the attending physicians. Additionally this provides a platform for Fundaleu's staff to meet and learn from leading figures in their focused areas.

What are the key features of the initiative?



There are seven x 1.5 day workshops comprised of nationally renowned experts. These workshops are funded by industry players, who are also responsible for inviting the attendees and arranging the logistics; up to 17 per event are invited.

The funding pharma body does not actively take part in the meeting, nor do they hold parallel meetings at the same time.

The seven workshop topics are MM, CLL, CML, lymphoma, MDS, AML, ALL and a specialist workshop on diagnostic and prognostic laboratory techniques and processes. In indication specific meetings, each participant will often be required to bring an interesting case to discuss/present.

The training helps to educate individuals from across Argentina working within the haematological malignancy space to implement better care. The knowledge, practices and resources can be brought back to regional centres and disseminated.

All Fundaleu staff can attend workshops to learn and get up to date with most recent practice.

Patient meetings are frequently carried out at the same time so that they can interact and ask about their own personal care. This is supported by the Max foundation. These meetings are split by age (<35 and >35) in order to maximise benefits due to different queries from these age groups.

What is the additional staffing requirement?



A coordinator to establish the workshops and invite suitable attendees.

What are the challenges faced by the initiative?



Getting high-profile specialists to attend and facilitates in workshops. Fundaleu's collaboration with the pharma industry, who play a role in selecting/recruiting participants for the workshops, handling the logistics in terms of travel and accommodation, helps to overcome this challenge.

What is the impact?



The impact of this service on the practice of physicians within the haematological malignancy space has had significant effect, with many implementing learnings in their practice and some gaining preceptorships with the influential physicians from across Latin America.

Resources have subsequently been disseminated to regional centres and internationally following these workshops, furthering their educational benefit.

These workshops provide content for individuals to take outputs in the form of abstracts to the National Haematology Society Congress.

Several other hospitals have followed this example and tried to replicate it, thus broadening the opportunity throughout the region to benefit from collective learnings.

What are the challenges of replicating this?



Receiving the right fundings, providing the correct type of training and getting the most applicable individuals to attend.



Rotational programs for regional HCPs



Overview

Training and educational programs provided to medical care team members across the haematological malignancy patient journey from the regional provinces, and some international physicians. This programme helps to educate and train physicians in good haematology practice, which they can subsequently bring back to their centres.

What is the rationale?



To increase the quality and level of care across Argentina, providing the opportunity for physicians across the region to learn from leading centre experts how to best implement care. Additionally these physicians will bring in new learnings from their regional provinces, which Fundaleu can learn from.

What are the key features of the initiative?



Fundaleu is a University Teaching Hospital associated to the University of Buenos Aires and offers specialised training to medical doctors in haematology.

Programmes offered include a Haematology Fellowship Programme of three years and a Haematopathology Fellowship Programme for two years.

The rotation programme has been set-up for doctors, nurses, lab staff and residents.

Argentinian nationals have been given priority in enrolling for the program, but it is also open to other physicians from across Latin America.

There are a variety of different haematological malignancy physician roles available for rotation through Fundaleu for differing durations:

- Haematologist rotation lasts for three months;
- Nurse rotation lasts for one month;
- Diagnostic and prognostic laboratory staff rotation lasts for one month;
- Care team members in residency positions remain in the programme for three years.



New positions are opened at a rate of around one per month.

The care team members will take their learnings back to their regional centres, where they can implement initiatives and good-practices learnt from Fundaleu.

Also used to advertise ongoing clinical trials to regional centres, who are then able to refer suitable patients for inclusion.

What is the additional staffing requirement?



No additional staff are required.

What are the challenges faced by the initiative?



Selection of the right participants and prioritisation of the physicians to come into Fundaleu. This process is conducted by the Assistant to the Medical and Scientific Director of the institute.

What is the impact?



Doctors rotating through and going back to their centres after rotation/workshops will be able to measure their own practices against the good practices developed and demonstrated in Fundaleu. Ultimately this will allow regional centres the ability to change their process to line up more closely with these good practices and in doing so improve patient care.

Regional centres will also have greater visibility over the clinical trial programme at Fundaleu and so will be able to refer suitable patients.

What are the challenges of replicating this?



Establishing relationships with regional centres to ensure they are aware of this programme and actively encourage the care team to partake in it.

Having the capacity and facilities to host visiting care team members for the duration of their rotation.



Haemato-pathology specialism



Overview

Fundaleu is one of the three-four hospitals in Argentina which provide second opinions for free. This way general hospitals are able to get opinions of the haematopathology specialist.

What is the rationale?



The vast majority of centres in Argentina and the Latin America region only have a general pathologist in-house. Lack of specialised haemato-pathology knowledge increases the chance for misdiagnosis or late diagnosis.

What are the key features of the initiative?



Each year a fellow from Argentina or Latin America who has just finished his/her training can apply for a two year specialist training programme in the field of haemato-pathology. Good and strong interaction between the haematopathologist and other laboratory specialities and services (e.g. IHC, molecular biology etc.) is seen as essential. This ensures that diagnoses and prognoses are as robust and accurate as possible. To enable this the haemato-pathologist is located in close proximity to other diagnostic specialities, creating direct communication channels. Formal meetings are also held to discuss patients (MDT meetings) in which the haemato-pathologist takes part.

Service which goes into the provinces to train local pathologists in haemo-pathology speciality.

This specialist training programme for haemato-pathologists has delivered the first and only haematopathologist in Ecuador.



It should be common for pathologists to work in haematology courses through the haematology society. It is key for haematologists to understand exactly what they need to send to pathologists, so close communication is essential.



Chief of Pathology Department

What is the additional staffing requirement?



If seeking in-house expertise, haemato-pathologist. If seeking access to specialism, there is no additional staffing requirement.

What are the challenges faced by the initiative?



Haematopathology is a speciality in crisis. There are only eight haemato-pathologists in the National Haematopathology Society. The cause of this is that there is a significant volume of training required to gain this qualification, and the salary for these positions is not viewed as sufficient, nor does it demonstrate parity with other specialities demanding similar training. Fundaleu runs a haemato-pathology training course to encourage this specialty, and trained experts go out to regional centres to disseminate learnings.

Additionally Fundaleu offers second opinions so that regional centres without in-house experts are able to access this speciality to benefit their own patients.

What is the impact?



Diagnosis is more accurate and timely ensuring patients' time-to-diagnosis and subsequently time-to-treatment is as short as possible. This results in improved patient outcomes.

What are the challenges of replicating this?



Speciality is not well-paid and consequently the number of specialists in Latin America is very low.

For centres wanting to access this specialist knowledge through second opinions, multiple biopsies and associated transportation costs are expensive and there is low insurance pay out for such services.



Access to genomic sequencing



Overview

Fundaleu has established a collaboration with the CEMIC University Institute in Bueno Aires to gain access to genomic sequencing (Sanger sequencing) techniques to help inform treatment decisions in myeloid neoplasms and acute leukaemias.

What is the rationale?



Genomic sequencing is becoming increasingly important as a tool to inform pragmatic decisions based on a robust knowledge of key prognostic markers. It allows haematologists to more accurately predict patient response to treatment and will drive the implementation of personalised therapy in the region. In the future, potential reimbursement decisions could be made based on a patient's genotype, increasing the importance of access to genomic sequencing.

What are the key features of the initiative?



Fundaleu collects 150 samples a month from potential haemato-oncology patients to confirm diagnosis and prognosis.

Samples are currently sequenced using Sanger sequencing technique in collaboration with the CEMIC University Institute in Buenos Aires.

Fundaleu are planning to implement next-generation sequencing in-house in the future, to ensure patient access to this technique and to the best treatment outcomes.

Additionally Fundaleu hold a two-day workshop/meeting with 15-20 laboratory professionals from Argentina and experts who specifically focus on harmonising the protocols between diagnosis treatment and follow-up.

What is the additional staffing requirement?



Technicians capable of performing sequencing techniques (if in-house).

What are the challenges faced by the initiative?



Genomic sequencing is an expensive technique, to which the majority of centres in Latin America do not have access. Initially Fundaleu addressed this issue through establishment of a collaboration with an academic institution capable of carrying out sequencing techniques. In future Fundaleu plans to bring this technique in-house.

What is the impact?



The impact of having full genomic sequencing could lead to more accurate diagnosis and prognosis for patients with haematological malignancy.

Haematologists will be able to understand which treatments will likely have the best response in each patient, aiding decision making and ultimately leading to improved clinical outcomes for patients.

In the future it may be required for reimbursement of specific treatments in the field, so implementation of this technique now prepares a centre for this potential future requirement.

What are the challenges of replicating this?



Building relationships with centres that have genomic sequencing capabilities.

Not all genome markers are equally informative regarding treatment decisions. These are under constant review as the research landscape/disease understanding evolves.



This technique will need to be made more accessible to the majority of centres, as personalised and targeted therapies become more readily available, to justify their use in specific patients.



Chief of Ultrasound





Weekly multi-disciplinary team meeting programme



Overview

Highly collaborative treatment environment between all key players in the care and management of haematological malignancies. Multiple formalised MDT meetings exist serving to address patient care and management in addition to team development.

What is the rationale?



Place for the team to challenge treating physicians and play an active role in contributing to each patient's treatment care and plan. This process ensures that the whole team is fully integrated and involved in each patient's care journey throughout their treatment. Ultimately this results in improved patient outcomes.

What are the key features of the initiative?



There are eight fixed MDT meetings per week. There is one every morning between 8-8:45am to discuss medications and share opinions. Other main meetings include:

- Monday morning: All the HCPs involved in delivering patient care meet to discuss Fundaleu's current patients ongoing and future treatment plans. This ensures better management across the patient journey. All care team members are actively encouraged to challenge treatment choices, if required.
- Monday afternoon: Specific forum for dissemination and discussion of interesting outpatient cases, with the goal of optimising the patient's treatment plan while also contributing to the development of the haematological malignancy team.
- Wednesday morning: This meeting serves as either a platform for academic literature review or discussion of a specific difficult case currently ongoing.
- Friday afternoon: The last multidisciplinary meeting of the week, to align on current patient care plans over the weekend.

These are unique learning platforms giving an opportunity to educate others in the team of all the new developments within cases, drugs, regulation and disease profiling.

The everyday 8am meeting is used to discuss the inpatients and anyone in ER as necessary, deciding which patients to discharge or admit, and plan chemotherapies. in advance of those who need it. These meetings include discussion with support of the haemato-pathology team, showing slides with their diagnostic findings.

What is the additional staffing requirement?



Care team member whose role it is to specifically develop and direct the MDT meeting schedule and organisation.

What are the challenges faced by the initiative?



Ensuring adequate attendance from the team members and commitment of time in busy schedules. It requires strong understanding of patients' profiles and their history.

What is the impact?



Each team works collaboratively to implement the best possible care for the patients. Learnings are shared between and across teams, ensuring ongoing development of the full care team body.

Accurate knowledge of the patient's history can ensure the best care is implemented.

What are the challenges of replicating this?



Setting up a comprehensive structure of MDT meetings every day requires good coordination, time and commitment from the team.

By ensuring that all care team members are engaged and actively participate in the MDT discussions will bring the maximum value to the meeting and ultimately to the patient.



ICU to the patient



Overview

All patient rooms in Fundaleu have the ability to accommodate mobile ICU facilities, effectively 'bringing the ICU to patient'. This means that the patient remains in the same care setting, reducing infection risk and maintain the same care team.

What is the rationale?



ICU capabilities are required mostly for cases of sepsis, high fever, low blood pressure, or when patients develop specific infections. Fundaleu wanted their patients to have continuity in their care across the treatment pathway through maintaining the same medical care team, which helps to build trust between the patient and physician and ensure better patient satisfaction. Maintaining the same context also removes the risks associated with moving the patient, such as the risk of infection.

What are the key features of the initiative?



This ICU system provides the patient with the same capabilities as a standalone ICU unit in a hospital setting.

Each of the 20 beds in Fundaleu can be converted into an ICU facility. The equipment (e.g. mechanical ventilator/O2 and monitor) is all mobile, allowing it to be brought into any patient room and set-up.

Mobile respirators are available for four patients at a time, for mechanical ventilation. This requires one therapist or ICU doctor to operate and ensure proper operation and monitoring of the initiative.

The family are allowed to stay with the patients, 24h a day. Therefore the relatives remain part of the treatment across the pathway, and help to consistently monitoring the patient as they would before.

The nurse originally responsible for the patient becomes 100% dedicated to that patients care, with the nurse coordinator taking responsibility for the remaining patients for which that the nurse was in charge.

The treating haematologist remains in charge of the patient while under ICU care.

What is the additional staffing requirement?



ICU physician to be mobile between different rooms of the institute.

What are the challenges faced by the initiative?



Establishing the infrastructure so that the ICU can be mobilised around patients requiring intervention in adequate time. Fundaleu had no problem implementing this initiative as was the original plan for the centre.

Having nurses fully trained for inpatient care and ICU care.

Ensuring that all nurses are trained in infection control. In Fundaleu, one nurse is responsible for delivering this training to the rest of the team.

Having a full-time physical therapist (Kinesiologist) covering 12 hours a day.

What is the impact?



This system ensures that ICU facilities can be provided to the patient in a much faster timeframe.

Continued access of the family to the patient is beneficial for the patient's satisfaction and mental state, helping to keep them positive and proactive in their care.

There is continuity of care for the patient, leading to better patient management due to knowledge of history.

There is reduced risk of infection.

What are the challenges of replicating this?



Having the human resources to be able to implement this rapid change around.

Privatised rooms that have the capabilities to be adapted to accommodate all ICU equipment.

Having the resources to procure mobilised systems.



Specialised haemato-oncology imaging services



Overview

Imaging specialist with background or training in haematology, who provides imaging services to haemato-oncology patients (ultrasound, tomography, radiology etc.), and who is able to provide follow-up on all related complications (e.g. stent insertion following cardiac complications).

What is the rationale?



Specialised haemato-oncology imaging practitioners will have comprehensive knowledge of all imaging signals relating to disease progression and treatment success in haemato-oncology patients. This reduces the risk of misdiagnosis or delayed diagnosis of a disease, and ensures that patient treatment is delivering the desired outcomes. Also complications arising for treatment can be actively identified and followed without haematologist intervention.

What are the key features of the initiative?



Fundaleu received donations of equipment and started implementing specialised imaging services in-house. The full patient journey is supported by the imaging department

The specialised imaging services are always available to both inpatients and outpatients. Order of imaging is usually ultrasound, then tomography then radiology (all efforts to reduce patient exposure to radiation are implemented). PET scan is available but through external associations.

Imaging can be carried out as often as required for each patient, as their state can differ from morning to evening.

The imaging department has strong relationships with the clinical department and therefore if they are to come across any unusual results they know who to share this information with quickly and efficiently.

The specialised imaging practitioner provides training for other fellows that come to Fundaleu to learn about imaging techniques, specifically in the haemato-oncology field.

What is the additional staffing requirement?



Imaging specialist with specific training in haemato-oncology related imaging services.

What are the challenges faced by the initiative?



Access to specialist imaging technology is a potential challenge. Fundaleu received the correct equipment through charitable donation.

What is the impact?



Faster outputs and results to patients, allowing to track the full imaging history of the patient. Specialist haematology knowledge allows the imaging practitioner to actively investigate side effects of treatment without haematologist intervention.

The imaging department is key to the follow-up of haemato-oncology patients and their state can differ from the morning to the evening. Thus they require constant follow-up to track treatment success and disease progression.

What are the challenges of replicating this?



Financing and funding of specialised imaging services, as these are mainly financed through the insurance companies.

Consistent interaction with the patient is essential in understanding the development of the disease.

Specialised knowledge is needed to ensure imaging is used to its full potential.



Specialised experience in haem-oncology imaging ensures that the imaging techniques are used to their full potential.



Chief of Ultrasound



Integrative oncology support services



Overview

First institute to offer integrative oncology support services free of charge to patients. These are additional supplementary services, such as acupuncture, that are aimed at improving the mental state of patients and their families.

What is the rationale?



Providing holistic support for the patients helps to improve their mental state which has been proven to play an important role in ensuring effective recovery. These activities are based upon strong clinical foundations with papers published in peer reviewed journals examining their benefits.

What are the key features of the initiative?



Fundaleu has a wide range of services available for both patients and their families. The services are delivered onsite, and include acupuncture; massage and reflexology; music therapy; mind/body support (including psychologist support) and TaiChi.

These services are provided free of charge, being funded in their entirety by the Fundaleu foundation. They are not reimbursed by any insurance or publicly available funding method (e.g. social security).

What is the additional staffing requirement?



Specialist practitioners of integrative services if required (e.g. TaiChi instructor).

What are the challenges faced by the initiative?



Integrative services are not funded by the public healthcare system. As such Fundaleu self-funded this initiative, through activities such as fundraising events.

What is the impact?



Holistic care services such as these have been proven to benefit the patients mental well-being as well as their physical recovery.

Patients reportedly say that having their family to support them is one of the most important factors in their care. Therefore having support available for the family as well is essential in ensuring they can play an active part in helping with their relations care.

What are the challenges of replicating this?



Due to it being supplementary care it is difficult to ensure funding to implement these integrative services at no additional cost to the families and patients.

Having the facilities and space to implement can be seen as a major barrier.

Obtaining and hiring the right staff present and available to implement these initiatives.



Patient care and support is the primary goal. All the staff are very close to the patients and their families.



Haematologist





'Care for Whom Cares' programme



Overview

This programme was specifically set-up to help and provide mental support for staff involved in treating and managing patients with often advanced or terminal haematological malignancy.

What is the rationale?



Throughout the course of working with and treating patients suffering with haematological malignancies, staff will be exposed to traumatic events. This programme was established primarily to allow staff a platform to discuss and share experiences, and to gain support and advice enabling them to deal with such events themselves. This aims to help staff cope and prevents burnout.

What are the key features of the initiative?



'Care for Whom Cares' programme happens once every two years and is provided for all staff at Hospital Fundaleu. The centre is looking for funding to increase the frequency.

Both the core team and wider support team are all able to enrol in this special service at Fundaleu which helps to support staff with the stresses and mental issues that they may experience as a direct result of working with patient suffering from advance/terminal diseases, such as haematological malignancies.

The format of this programme is a group discussion during which staff are able to discuss any issues and concerns they are having. They encouraged to speak about any psychological and mental effects they feel are caused by the experiences they have through delivering care to patients. A psychologist or mental support professional takes part in this programme to ensure support can be adequately provided if and when it is required.

Participation in the programme is optional for all staff.

What is the additional staffing requirement?



Psychologist/mental health professional to support the programme and provide support to staff members where required.

What are the challenges faced by the initiative?



Because the discussions are held within a group setting, some individuals feel that they are unable to share personal issues or problems within a group setting.

Funding has been an issue for this programme, as Fundaleu has been attempting to get reimbursement but has not yet succeeded. Currently the Fundaleu foundation provides all of the funding, though fundraising events, charitable donations etc.

What is the impact?



The whole care delivery team feels more emotionally supported by the institution and mentally strong to maintain the high level of care required.

There is reduced risk of burn out of staff looking after patients.

What are the challenges of replicating this?



There is difficulty in obtaining the funding to run these support programmes.

Ensuring the establishment of an environment whereby the staff feel comfortable explaining their ongoing issues to ensure they are adequately supported.



There is a very low rate of attrition in the staff, as a result they are well embedded in the Fundaleu system. Patients get to know them well and trust them.



Chief of Haemotherapy



Americas Centro de Oncologia Integrado

Rio de Janeiro, Brazil

—
KPMG, June 2017





Americas Centro de Oncologia Integrado (COI) outpatient unit works collaboratively with specialised centres to deliver continuous patient care

Key findings from the centre



Network of established centres for care delivery

- COI provides care through a network of specialised centres. For example, six in- and out-patients units belonging to Gruppo COI and Americas Health City and BMT unit at Complexo Hospitalar de Niterói, that work in alignment to provide continuous care to patients.

Close collaborations for scientific research and good practice

- Physicians work in very close collaboration with multiple experts (e.g. for Scientific Advisory Boards), institutions (e.g. COI Institute for Clinical Research) and other hospitals (e.g. network with INCA, Sírio Libanes and other hospitals) to define good practice.

Commitment to quality control

- A dedicated team ensures quality control throughout the hospital, capturing multiple patient outcomes which are reviewed prospectively and retrospectively to assist in decision making and improving clinical care of patients.

Key challenges faced in the delivery of haematological malignancy care



Improved diagnostic capabilities at a national level

- There is a shortage of specialist pathologists, and high-quality and consistent output from laboratories leading to delayed and misdiagnoses. This continues to be a problem within both the private and public sectors. For example, within the private sector, variations in insurance coverage means the same hospital may need to use several laboratories for diagnostics; leading to inconsistencies in quality and time to diagnosis.

Restrictions on high-cost medications

- Access to new and high-cost medications continues to be a key issue; with limitation in coverage under standard insurance schemes. While trials are a routine method of access; greater engagement and alignment among healthcare policy makers is required to reduce delays in access.

Legal acts for access to treatments and medicines

- Due to the nature of the regulatory and legal systems, 'legal acts' by patients requesting access to medication not covered by insurance is common. This has fuelled an industry around these, and can lead to disputes between providers, insurers, industry and patients. Managing these to ensure continuity of relationships has become a key consideration for many providers.



The outpatient unit is a member of a six-hospital conglomerate

Haematological malignancy specialty unit



Services:	Private hospital conglomerate comprising six hospitals. JCI and ANA (national Brazil) accredited. This report focuses only on the outpatient unit.	Collaborations:	Multiple collaborations for specialist services, including BMT.
Resources:	Outpatient unit comprises of 71 infusion chairs/beds; an ambulatory ICU unit and procedure room. On-site pharmacy.	Funding:	Privately owned by United Health.
Teaching:	Multiple training programmes including internal (specialist nurse training) and external (physician training for BMT eligibility).		

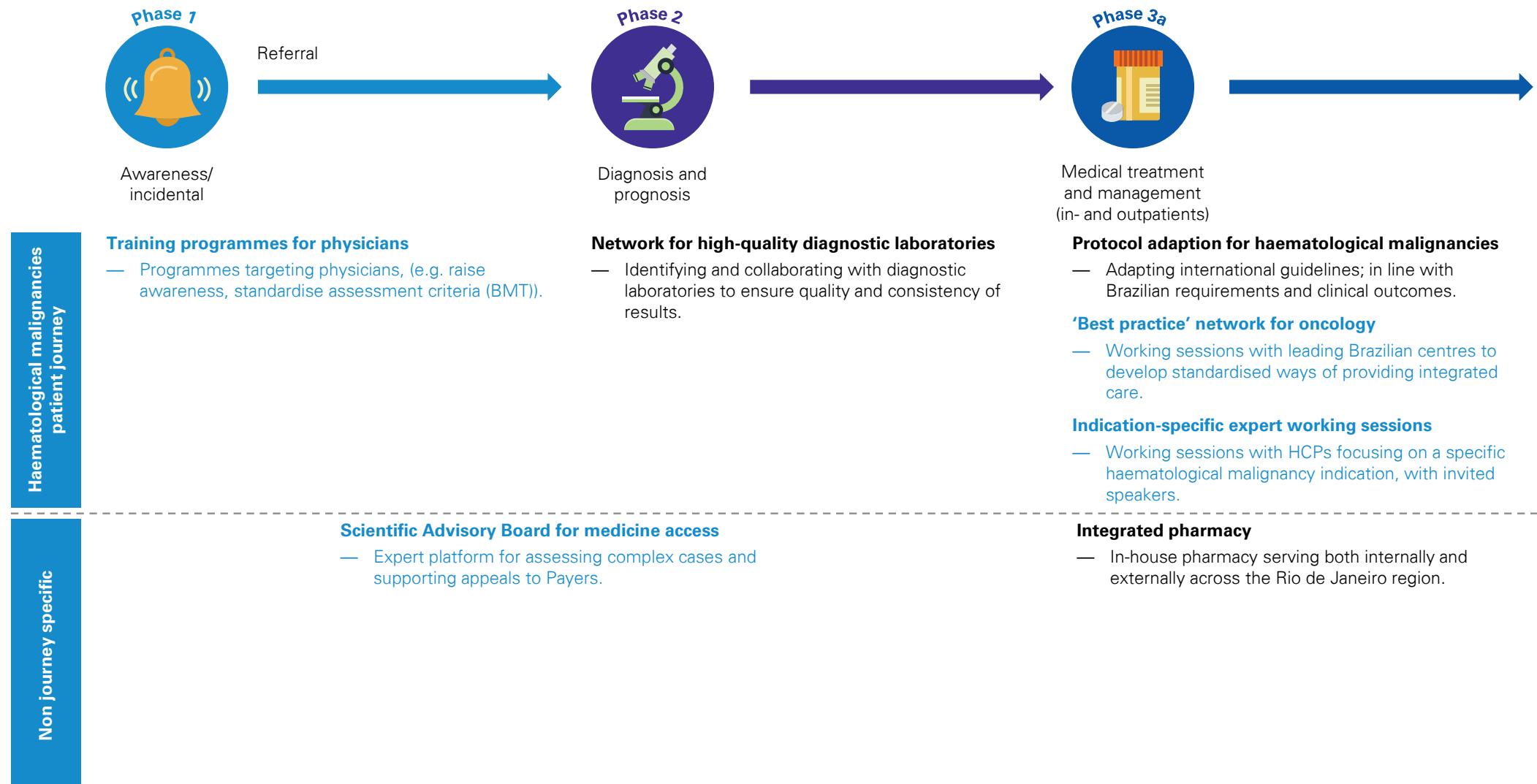
The patients



Geographic scope:	Wider Rio de Janeiro region, Brazil.
Patient population:	Primarily adult patients with private insurance cover.



The unit has established a number of initiatives to improve patient care





Blue text = Case study available



Phase 3b
Bone marrow transplantation



Phase 3c
Monitoring and follow-up



Phase 4
Palliative care

Specialist network for BMT care

- Close collaborations with hospitals specialising in BMT.

Day clinic for outpatients

- Regular follow-up programme offering integrated care (may be up to one year post-discharge).

Sponsored care

- Limited palliative care offered free of charge to patients (funded by COI, as it is not covered by Payers).

Nurse training programme

- Internally developed training programme to up skill and standardise nursing care .

Haem-onc pharmacy

- Integrated pharmacy in house for all chemotherapy drugs.



We are a highly-specialised team that is one of the best in Rio for both out and inpatient management, and we work very closely together to deliver best possible care.



Haematologist



A highly-specialised team is available for close patient management

Key features of the haematological malignancy care delivery team:



- A highly-specialised team of haematologists who work in close collaboration with integrated care specialists (e.g. psychology) to deliver care in an outpatient setting.
- Specialist nurses who are trained on-site, to manage all aspects of patient care.
- A network of specialists (e.g. BMT) and in-patient facilities to ensure continuity of care.
- Continued and regular training out in the community to improve linkage to care.

Governance and processes



Team meetings:

Multiple external meetings (e.g. scientific meetings) conducted regularly. Ad-hoc MDTs held for patient management.

Patient records:

Electronic records available for all patients. Prescriptions cannot be developed electronically, as manual signature is needed.

Pharmacy:

Integrated pharmacy that supports outpatient unit as well as the majority of hospitals within the Rio de Janeiro region.



How can haematological malignancy care be improved?

What is next for the centre?



Provision of palliative care

Palliative care is often not covered under the public system or within private plans. While at COI limited palliative care is provided to patients for free (funded by COI); there are opportunities to expand this further, particularly into ambulatory or home care.

Diagnosis (time to diagnosis and quality)

Access to high-quality and consistent diagnostics is limited. Although COI has a network in place of preferred partners, laboratories are often chosen by price and not quality by the Payers. Further; certain tests, such as FISH, are often not covered. Therefore, there is a need to improve the time and quality of diagnostics.

Systematic use of outcomes data

Clinical outcomes are tracked at COI, but there is an opportunity to do this more systematically at a regional or national level. This would require implementation of national registries and process for analysis and dissemination. There is also an increased need to track Patient Reported Outcomes (currently primarily clinical outcomes are tracked).

What advice would you give to less-specialised centres?



Develop specialist networks

Identifying and developing networks with preferred partners who can provide consistent and high-quality specialist services, (e.g. BMT is important to ensure continuity of care).

Implement quality control

Quality control initiatives, while often difficult to implement, have a significant impact on providing high-quality care (e.g. providing feedback for protocol amendment through retrospective analysis). Ensuring support that is top-down, and initiating with small pilots (e.g. 20 patients with leukaemia) to demonstrate effectiveness can be successful.



Case studies



Training programmes for physicians



Overview

COI runs a series of targeted training programme aimed at physicians. These address multiple objectives including increasing awareness of COI services and recognising BMT eligibility in patients.

What is the rationale?



The level of knowledge among physicians, particularly in primary and secondary care settings can vary and there is a need to standardise knowledge and approaches to ensure greater accessibility and improved patient care.

What are the key features of the initiative?



The haematological malignancy team work closely with COI's 'Relationship with Doctors' department to identify and develop training programmes. The department maintains a database of physicians from the region, which is used as a planning tool. This department also supports in the production of training materials, (e.g. educational brochures and web pages).

Example training programmes for physicians include:

- BMT eligibility: information on how the patient can be evaluated, including clinical indications, contra-indications etc. Objectives are to standardise how patients are assessed. The target audiences are primary and secondary care physicians in the Rio area.
- Referrals to COI: programme for physicians from the wider region who do not currently refer patients. Provide advice on how best to refer patients. The objective is to ensure wider patient access and minimise referral times.

What is the additional staffing requirement?



No additional team members needed; however time dedicated to developing and running training programmes, as well as funding for collateral is needed.

What are the challenges faced by the initiative?



Identifying the right physicians to engage with, and maintaining long-term relationships to ensure information sharing and feedback collection. Developing the right level of information that is useful and relevant to the audience.

What is the impact?



Standardisation of patient assessment and referrals; various metrics are tracked, (e.g. number of referrals per month).

What are the challenges of replicating this?



Dedication of time and resource to material development.
Developing and tracking of metrics for impact.
Identification and engaging with correct physicians.



'Best practice' network for oncology



Overview

Standardised and integrated care is a key criteria for high-quality patient management. A working group of experts from leading hospitals can provide means by which good practice care is agreed and disseminated.

What is the rationale?



To ensure consistent and high-quality patient management, standardised and integrated care is critical. While international guidelines provide an evidence-based standard of care, variations in medicine availability and funding constraints means it is necessary to adapt these guidelines to suit local requirements. Further, provision of integrated care is a critical aspect of high-quality patient management. Standardising these across the country is important for providing consistent quality of care to patients.

What are the key features of the initiative?



A working group comprising experts to meet, discuss and drive standardised oncology care in Brazil.

Format:

- Regular meetings with oncologists from leading hospitals across Brazil, including INCA, Hospital Samaritano, Centro Paulista de Oncologia and COI and others.
- Some aspects (e.g. meeting spaces) may be industry sponsored.

Aim:

- Develop standardised protocols for treatment.
- Share knowledge on treatment options including new medications.
- Share 'best practices' in integrated patient management.
- Discuss alignment on HMO and Payer relationship management.

What is the additional staffing requirement?



No additional staff required; time requirement for participation in network and follow-up activities.

What are the challenges faced by the initiative?



Funds for running meetings and time requirements from healthcare professionals; addressed through working with industry for sponsorship and ensuring benefits of working group is evident to encourage participation.

What is the impact?



Provide standardised and integrated care to patients. A pilot is currently underway (in breast cancer) to assess possibility of improved reimbursement for centres which provide standardised and integrated patient care.

What are the challenges of replicating this?



Ensuring buy-in and therefore active participation from oncologists.

Organisation and logistics of coordinating leading oncologists from across the region.



Indication-specific expert working groups



Overview

Workshops focused on specific indications in haematological malignancies are run every two weeks; providing opportunities for physicians to share ideas and learn.

What is the rationale?



The heterogeneous nature of pathologies within haematological malignancies require specialised knowledge to provide personalised patient care. This required in-depth understanding of pathology, prognostics and patient management (including comorbidities). Engaging with other physicians provides an opportunity to share ideas and learn from the wider community.

What are the key features of the initiative?



Working sessions with physicians from Rio specialising in each haematological malignancy indication (e.g. CLL, CML or MM) brought together to discuss a number of key topics:

- Diagnostics and prognostics.
- Personalised treatment paradigms.
- Processes and practices in patient management, including complex cases.
- Challenges with access and how these can be addressed.

Specialists from other regions are invited as guest speakers on a regular basis.

Industry sponsorships are in place to cover expenses (e.g. venue cost or refreshments).

What is the additional staffing requirement?



Resources required for admin (e.g. organisation) and hosting (e.g. venue costs).

What are the challenges faced by the initiative?



Ensuring injection of new information to increase knowledge and skill set of the group on a regular basis; this is addressed by discussing latest scientific literature, guidelines and inviting guest experts to speak at the events.

What is the impact?



There is an improvement in the understanding of disease management in haematological malignancies with physicians across the treatment pathway.

The provision of more personalised care for each patient.

What are the challenges of replicating this?



Dedication of time and resources for the organisation.



Day clinic for outpatients



Overview

A drop in Day clinic for outpatients, with access to dental, dermatology and psychology on top of haematology-oncology services.

What is the rationale?



Haematological malignancies are chronic conditions, and relapses are common. There are limitations in patient and community physician ability to adequately monitor patients and recognise signs of relapse. Therefore processes for contact are important to ensure regular monitoring and continuity of care.

What are the key features of the initiative?



A drop in day clinic providing integrated services to patients.

Organisation:

Patients are followed up once per week or every two weeks post-discharge. A suite of integrated services are offered:

- Haematology-oncology;
- Dermatology;
- Dentistry;
- Infection control;
- Nurse support;
- Psychology.

Eligibility:

Offered to all patients, particularly those post-BMT. For patients who have undergone an allogenic transplant this service offered for up to one year post discharge.

What is the additional staffing requirement?



Dedicated resources required to staff clinic; across all integrated specialities.

What are the challenges faced by the initiative?



Ensuring continued patient engagement; which is addressed by nurses/admin teams remaining in close contact post-discharge, e.g. phone call reminders to patients when clinic visits are due.

What is the impact?



Greater convenience for patients as they are able to manage time.
Improved patient safety and outcomes as they are subject to regular follow up.

What are the challenges of replicating this?



Dedication of time and resource required to effectively run the clinic.
Adequate infrastructure (e.g. location for clinic).
Effective processes in place to maintain contact with patients (e.g. for follow up of patients, regular contact).



Scientific Advisory Board for medicine access



Overview

An expert Scientific Advisory Board to validate requirements for access to medicines not usually available (e.g. not approved in Brazil, not covered by Payers).

What is the rationale?



Medicine access continues to be challenge in haematological malignancies, particularly given the pricing of the new targeted therapies that are entering the market, which are often not covered by Payers. Further, access may be limited by the lengthy processes in place for approval in Brazil (e.g. approval by ANVISA, approval by ANS for the private healthcare sector).

In Brazil, this has resulted in a trend of patients filing 'legal acts' with courts, which compel Payers to cover a medicine at market price.

To improve this situation, COI has in place a SAB who review cases of patients requiring high priced therapies, and build evidence-based cases for each. This supports in maintaining good relationships with the Payers and ensuring timely access to medicines.

What are the key features of the initiative?



An expert panel regularly meet to discuss access to medicines that are currently unavailable. This may be medicines that are 1) not ANVISA approved; 2) ANVISA approved but price not agreed; 3) ANVISA approved, price set but ANS approval not available for private sector; 4) specific indication not approved (e.g. off-label use).

The team comprises members with specific scientific expertise, and are brought together as required (e.g. MM experts for case on MM). The team discusses cases where specific medicine access is required and develop a relevant evidence base (e.g. peer reviewed publications or outcomes data).

Only cases where scientific evidence is available, and the group recommends use of the medicine, are put forward to the Payers. This circumvents the challenges around legal acts, particularly those promoted by third parties (e.g. pharma companies).

What is the additional staffing requirement?



No additional staffing requirement; dedicated time and venue may be required to hold meetings.

What are the challenges faced by the initiative?



Ensuring Payer concerns are acknowledged; this is addressed by maintaining close relationships and regular contact.

What is the impact?



Develops a clear, peer-reviewed evidence base for gaining access to medicines not currently available.

Limits physician prescription of off-label treatments without required evidence base; Helps maintain good relationships with insurance companies as a technically and scientifically diligent process is followed.

What are the challenges of replicating this?



Availability of time and resource availability of hold meetings.

To collate and develop the right information and documentation required to be shared with Payer(s).

To initiate and maintain relationships with Payers.



Institute of Cancer Sao Paulo (ICESP)

Sao Paulo, Brazil

—

KPMG, January 2018





Institute of Cancer, Sao Paulo (ICESP) is a focused institution dedicated to the provision of state-of-the-art care across the patient pathway for oncology patients

Key findings from the centre



Large well-resourced centre

- ICESP is funded through the public healthcare system, and as one of the major cancer centres in the country, it owns and operates a large number of state-of-the-art facilities. Due to this it is able to provide care and treatment to a large number of patients from across Sao Paulo and the wider country.

Fully integrated care team

- Care and management of patients with haematological malignancies is well managed and coordinated by all the key stakeholders involved in care (e.g. physicians, nurses, psychologists etc.). All specialisms are present throughout the full patient journey, extending beyond treatment into follow-up.

Large presence in clinical trials

- ICESP represents one of the largest centres for clinical trials in the country. Almost all haematological malignancy studies are at least in part conducted here. This is due to their reputation as a hospital, their link to the University of Sao Paulo, and the presence of a highly credible team.

Patient centric care

- There is a strong focus on providing a 'humanized' service to the patient and their family. Physicians and the wider care team are trained specifically to use appropriate language in communication with patients, and to understand and consider holistic aspects such as the patient's cultural background during their interactions, and when prescribing treatment regimens.

Key challenges faced in the delivery of haematological malignancy care



Improved diagnostic capabilities at a national level to increase time-to-diagnosis

- Due to a shortage of haemato-pathologists within the public healthcare system in Brazil, blood or fluid samples of biopsies need to be sent to specialised centres and laboratories for diagnosis, leading to delayed and sometimes misdiagnoses. This results in long time-to-diagnosis metrics, which has the knock-on effect of delaying the patient's linkage to treatment. In the case of acute or serious haematological malignancies, this may have consequences for the patient's health outcomes.

Lack of funding

- Applications for funding for new equipment may be delayed due to bureaucracy of the healthcare system. Nowadays the top challenge facing cancer care is the continuous increment of costs of cancer drugs.

Public healthcare capacity shortage

- Some oncology centres in the public healthcare system have been closing in the last few years. This in turn has conferred a larger burden onto ICESP as there are an increasingly limited number of alternative centres for patients. Moreover, the social and economic implications of an aging population is also a big challenge involved in cancer care.

Legal acts for access to treatments and medicines

- Due to the nature of the regulatory and legal systems, 'legal acts' by patients requesting access to medication not covered by insurance is common. This has fuelled an industry around these, and can lead to disputes between providers, insurers, industry and patients.



ICESP is a large-scale public hospital, accepting patients from across the Sao Paulo state region and beyond

Haematological malignancy specialty unit



Services:	Public hospital. JCI accredited.	Collaborations:	Collaboration with both the State and City Departments of Health - patient regulation; Casa Hope – patient residence.
Resources:	28-level hospital dedicated to cancer care; Inpatient unit; Outpatient unit; 2 PET scanners, 6 CT scanners; On-site centralised pharmacy, and one specific to each floor.	Funding:	State funded in its entirety.
Teaching:	Training programmes are run for both ICESP staff and external organisations. There is a dedicated floor for teaching, with classrooms and simulation rooms. E-learning platforms for specific disease area are also available.	Haematologist(s):	There are 19 haematologists in the team, providing services to both ambulatory and inpatients.

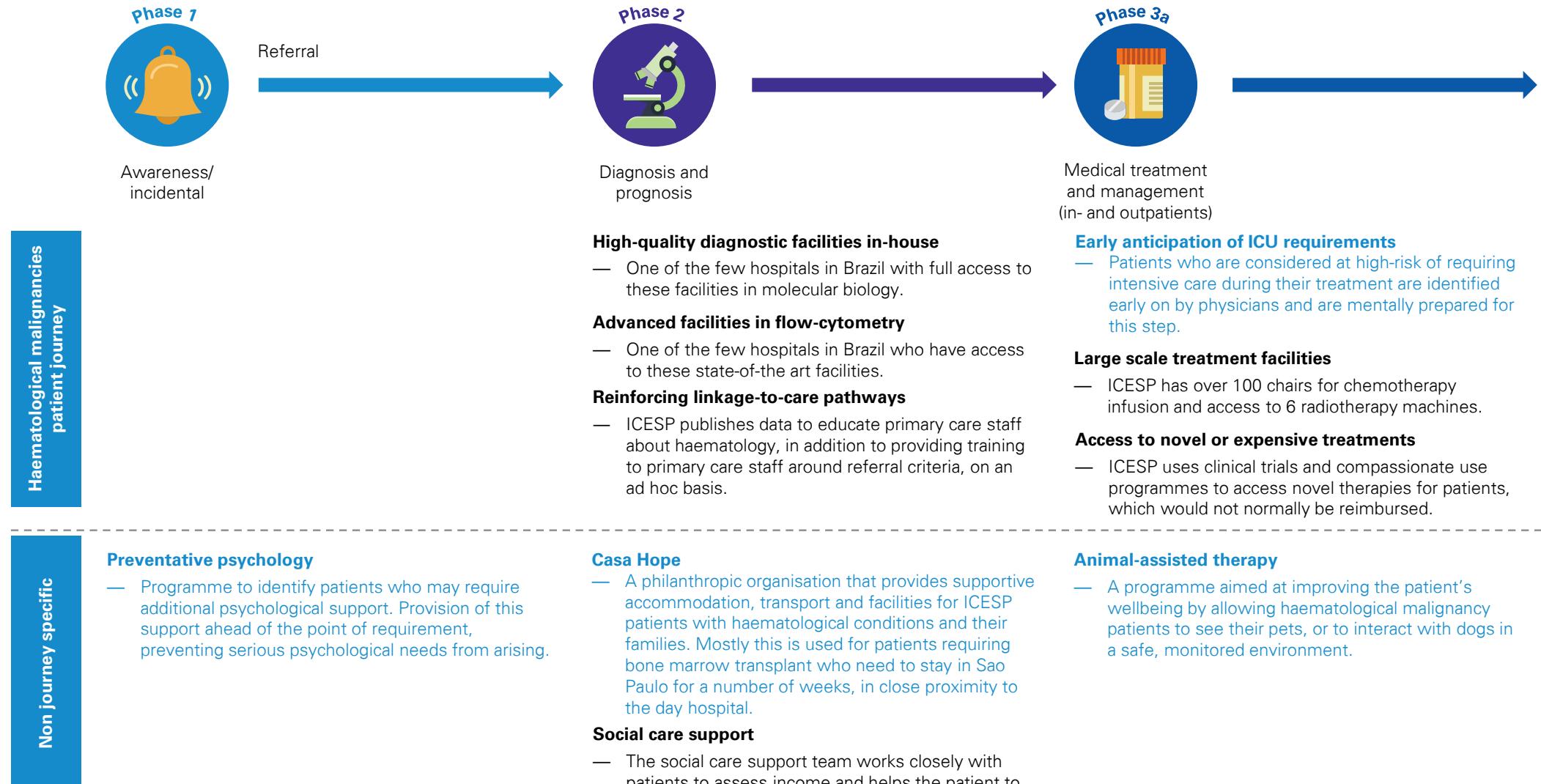
The patients



Geographic scope:	Generally from Sao Paulo, and the wider Sao Paulo state. A small number of referrals from patients across Brazil.
Patient population:	Adults who have a clinically confirmed diagnosis of cancer from a primary or secondary care setting.
Number of patients:	Approximately 6000 cancer patients are seen per month. There are 45 beds devoted to haemato-oncology.
Patients' characteristics:	Patients who have an existing, clinically validated diagnosis (or strong suspected diagnosis) of cancer.



The unit has established a number of initiatives to improve patient care





Bone marrow transplantation



Monitoring and follow-up



Palliative care

Blue text = Case study available

Purple text = Case study of initiative influencing wider healthcare landscape

Early discharge programme

- An optional programme for patients, enabling them to return to their homes sooner, reducing both the patient and hospital burden conferred by long periods of hospitalisation.

Full range of BMT services

- Donor searches are run through INCA, and haplo-identical transplant explored if finding a donor proves difficult.

Dedicated data managers

- Staff within the haematology department are given defined roles for managing data collection to ensure that data is effectively captured.

'Hello Nurse' programme

- A service offering contact to a nurse for patients and their family members 24 hours a day via telephone to answer any questions or concerns that may arise and to provide remote interventions for symptoms arising from treatment or disease.

Patient engagement

- An induction programme to educate patients around the treatment pathway in ICESP, ensuring they adequately understand the requirements and are fully engaged in their treatment.

Group setting support

- Group sessions are held for patients and their families to openly discuss the major issues and concerns they have regarding their disease and treatment regimen.

Patient regulation

- ICESP developed a detailed procedure which was adopted by the State Department of Health to help regulate the diagnosis and centralise patient dissemination across the cities hospitals.



A highly-specialised team is available for close patient management

Key features of the haematological malignancy care delivery team:



- Strong multi-disciplinary team setting, with all specialisms fully integrated across the patient journey.
- Haematology team with specialised focus by indication, but capable of working across indications.
- Specialised haemato-oncology nursing and support team working closely with patients and family members, to ensure patient-centricity in care delivery.
- Extensive programme of psychological support for patients and their families at all stages of the patient journey and through multiple initiatives.
- Proactive anticipation of complications, with risk-stratification processes in place to address these before they become serious.
- Close collaboration with the ICU team, and education around implications of ICU admission for patients and families ahead of time.
- In-house access to the full range of state-of-the-art facilities (e.g. PET-CT scanners, radiotherapy machines etc.).
- Extensive offering of integrative services (e.g. music therapy, animal-assisted therapy etc.).
- Dedicated staff coordinating linkage into care for newly diagnosed patients in primary and secondary care setting.
- Strong focus on education and training, with a full suite of educational materials and simulators (additionally used to train patients and their families in self-care).

Governance and processes



Team meetings:

Weekly MDT meetings for haematology (one for complicated cases, one for new admissions) and bone marrow transplant. Twice weekly meetings to discuss infection control.

Patient records:

All medical records held in the centre are on the electronic system, which is accessible to all members of the haematological malignancy care team within the centre.

Pharmacy:

Centralised pharmacy system with specialist haemato-oncology pharmacies on each of the 28 floors on the hospital.



Patients are always so thankful after their treatment in ICESP, which makes us very proud of the work we do here.

Nurse, Haemato-oncology





Case studies



Early Discharge Programme for bone marrow transplant patients



Overview

The Early Discharge Programme is an optional programme for patients, enabling them to return to their homes sooner, reducing both the patient and hospital burden conferred by long periods of hospitalisation.

What is the rationale?



Patients undergoing bone marrow transplantation are often required to remain hospitalised for extended periods of time. This confers a burden both on the patient's quality of life (including their family), the hospital in terms of bed occupancy and the public healthcare system with respect to financial requirements. By establishing a programme by which patients are able to be discharged from the hospital setting sooner, these burdens are all alleviated, conferring a benefit to all parties.

What are the key features of the initiative?



The key feature of this programme is to ensure that bone marrow transplant patients are discharged from the hospitalised setting as quickly as possible. This helps to reduce the potential susceptibility of infection (especially to multi-resistant bacteria) and in doing so it helps to create more capacity for those patients who require hospitalisation.

In this programme the patients are hospitalised for a period of around 1 week, during chemotherapy administration and the infusion. Following this the patient is discharged from the hospital. The patient is subsequently followed-up in the outpatient setting every day, and is able to access the emergency room at any time should complications arise.

There are specific criteria which need to be met for the patient to be eligible for this programme:

1. The patient must be considered safe for discharge by their treating physician;
2. The patient must reside within 1 hour of the hospital;
3. The patient must be between 6 years old and 60 years old;

4. The patient must have an family member/carer who can help to provide care and support within the home setting, as well as assist in transporting the patient back to hospital should the need arise. This can be a family member or a member of a volunteer organisation.

This programme is optional for patients.

What is the additional staffing requirement?



There is no additional staffing requirement for this programme.

What are the challenges faced by the initiative?



Patient's home conditions must be suitable to support the treatment/recovery process, and the patient must be capable of managing their lifestyle to ensure that the risk of complications, such as infection, are kept to a minimum.

This may require additional time from outpatient staff in order to manage the increased follow-up requirements.

What is the impact?



This benefits the patient quality of life as they are able to return home sooner, in addition to benefitting the patient's family.

The centre is able to free up bed capacity in the inpatient setting sooner, allowing more patients to receive treatment in a shorter time period.

This also reduces costs to the public healthcare system per patient, as they spend less time in the inpatient setting.

Approximately 60% of ICESP patients are on the early discharge programme.

What are the challenges of replicating this?



Ensuring continuity of care is maintained between the inpatient and the outpatient setting represents a significant challenge to the provision of high-quality care.

Ensuring the patient understands the disease significantly enough to self-care.



'Hello Nurse' programme



Overview

A service offering contact to a nurse for patients and their family members 24 hours a day via telephone to answer any questions or concerns that may arise and to provide remote interventions for symptoms arising from treatment or disease.

What is the rationale?



When patients are discharged from hospital, there is the risk that the patient and their supporting family members feel isolated, and they may struggle to know how and when to seek professional support or advice for questions regarding treatment, new symptoms etc. This can lead to the patient being lost from follow-up, or a reduction in the clinical/patient outcomes due to questions regarding key aspects of the treatment going unanswered.

What are the key features of the initiative?



The 'Hello Nurse' programme is staffed by clinical oncology and the haematology nursing team (40 nursing hours/day and 24 nursing hours at the weekend) and has four main goals:

1. To clarify the doubts of patients/family members, about medicines used in the treatment regimen, preparation of exams, clinical issues for relevant patients and guidelines provided by physicians while in hospital.
2. To allow for early detection of new symptoms arising as a result of treatment or disease progression.
3. To provide pharmacological and non-pharmacological management of symptoms arising from cancer treatment, based on institutional guidelines and protocols.
4. Carry out monitoring of VO antineoplastic therapy as well as management of toxicity.

To provide this service, the following facilities have been established:

- Three computers with access to electronic patient medical records.
- Three fixed telephones operating from 0700 to 2000.
- A mobile phone service for out-of-hours contact (i.e. 2000 to 0700).
- A comprehensive collection of the centre's protocols and guidelines for the management of oncology-related aspects (i.e. treatments, new symptoms etc.).

To ensure the patient and their family members are aware of this, they are informed of the service by the nursing staff during the initial nursing contact in the hospital, as well as at all times during care provision by the nursing staff.

Nurses are able to review all patients electronic medical records during the phone call to ensure they have all of the relevant information to allow them to give the patient advice.

The 'Hello Nurse' programmes is also used to make contact with patients, to inform them of changes in appointment schedules, consultations, treatments and procedures.

What is the additional staffing requirement?



There is no additional staffing requirement this role is performed by nurses already established in clinical oncology and the haematology department.

What are the challenges faced by the initiative?



Ensuring that calls at any time can be answered by a nurse, and that the clinical oncology team and the haematology nursing team has protected time to conduct this programme.

Monitoring of missed calls and following up in a suitable manner/timeframe – ICESP has set a target of responding to missed calls within 3 hours.

What is the impact?



The patient has access 24 hours a day to a trained professional ensuring that any doubts they have about their treatment of care can be quickly resolved.

Any symptoms arising from the treatment or disease can be identified early, and intervention applied early.

Gives the patient comfort knowing that they have support whenever it is needed.

What are the challenges of replicating this?



Ensuring that nurses have access to accurate, detailed medical records such that they can offer suitable advice to the patients.

Ensuring that the nursing team have sufficient capacity to man the telephone 24 hours per day, and that robust protocols are in place to follow-up on missed calls should this happen.



Early anticipation of ICU requirement and psychological preparation



Overview

Patients who are considered at high risk of requiring ICU intervention at some point during their treatment are identified early on in their treatment by physicians. This allows the patient to be prepared ahead of the requirement.

What is the rationale?



The intensive care unit (ICU) is occasionally required to support patients who require mechanical respiratory support or other highly intensive life support interventions during the course of their hospitalisation. Due to the perceived life-threatening status associated with a requirement for ICU intervention, along with the nature of the ICU environment itself, can confer a significant point of fear and anxiety for both the patient and their family. By identifying high-risk patients ahead of time, this can be addressed directly, mentally preparing the patient and family members for this eventuality.

What are the key features of the initiative?



The treating physicians in the haematology department are responsible initially for identifying any patients who may be considered high-risk for ICU intervention at some point during their hospitalisation. This identification is performed at the point of the patient's admission to the department.

The haematology and ICU physicians are then able to then explain the process to the patient and their accompanying family members, explaining the importance and processes of a potential ICU involvement.

Additionally the treating physician is able to involve the psychologist in this process, to help with the discussion and to further enable the patient and family members to understand the role of the ICU, and the potential for its involvement.

All of this allows the patient and family members to be mentally prepared ahead of time, reducing the levels of anxiety and fear associated with the ICU.

What is the additional staffing requirement?



There is no additional staffing requirement.

What are the challenges faced by the initiative?



The physicians must define a suitable criteria to identify patients considered 'high-risk' of ICU involvement. Additionally on-hand psychologists must be available to support the discussion around potential ICU intervention, for both the patient and their family members.

This process can be particularly challenging when younger children are involved in the family member group.

What is the impact?



Patients and their family members are mentally prepared for potential ICU involvement, meaning that should the requirement occur, they remain calmer. This will aid the physicians in delivering better care to the patient as they will not have to manage the family at the same time.

What are the challenges of replicating this?



Robust communication between the ICU physicians and the haematology physicians is essential to develop 'high risk' criteria and to coordinate care effectively.



Dedicated data managers



Overview

Staff within the haematology department are given defined roles for managing data collection to ensure that patient's data is effectively captured.

What is the rationale?



Capturing of outcome and quality data across the patient journey is essential to ensuring that the processes defining the care and management of patients with haematological malignancies are effective. By assigning the responsibility of capturing specific data sets to individual staff members, the speed, quality and consistency of data capture is improved. Analysis of this data would allow the institute to assess the effectiveness of its processes and protocols, and to adapt these in order to improve all aspects of patient care and management.

What are the key features of the initiative?



Haematologists within the hospital are assigned specific responsibilities with respect to capturing data. Currently data manager roles have been defined for the following data processes:

- 1 data manager dedicated to collection of data to be shared with the CIBMTR registry.
- 1 data manager dedicated to capturing data for internal projects (e.g. retrospective analyses of treatment outcomes).
- Other dedicated data managers are assigned by indication, responsible for capturing data not currently being assessed.

What is the additional staffing requirement?



There is no additional staffing requirement.

What are the challenges faced by the initiative?



Establishing systems for recording data which are quick to use and easily accessible for all treating physicians.

Managing the data in a confidential manner and aligning this with requirements for handling of patient data (where patient data is being collected).

What is the impact?



This initiative ensures that data is efficiently and comprehensively collected and therefore can be accurately measured against protocols across their treatment pathway.

A better data repository allows for more effective analysis of the service provision of the centre, and can lead to an evidence-based development of initiatives to improve overall care to patients with haematological malignancy.

What are the challenges of replicating this?



These roles are in addition to the existing roles performed by haematologists in the centre. Therefore physicians need to have enough capacity to be able to handle this additional responsibility in addition to their day-to-day roles.



Preventative psychology



Overview

Programme to identify patients who may require additional psychological support. Provision of this support ahead of the point of requirement, helps to prevent serious psychological needs from arising.

What is the rationale?



Patients with haematological malignancy and their families are generally considered in high need of psychological support throughout the course of their treatment and beyond. Psychologists working in a fully integrated multi-disciplinary team setting are in a unique position to identify and address potential issues before they arise or become exacerbated. In doing so they are able to better manage the patient's state of mind, rather than trying to rescue patients from periods of crisis. By identifying and addressing psychological issues before they become significant, positive health outcomes can be maximised.

What are the key features of the initiative?



The psychology team identifies patients considered to be at high-risk of significant psychological support throughout the course of their treatment, ahead of time. To do this there is a set criteria used to identify potential candidates of high-risk, and who may be in need of preventative psychological support. This includes:

1. Mortality risk – If a patient is considered to represent a high mortality risk, both the patient and their family are given priority support from the psychologist.
2. Long-term care – Those patients in long term care (i.e. hospitalised for extended periods of time) are considered as having elevated needs for psychological support.
3. Pre-transplant patients – Due to the processes associated with BMT, and the high patient burden, these patients are afforded priority psychological attention.
4. ICU risk – those patients who are at a progressive stage in their disease and are likely to require intensive care services during their stay.

What is the additional staffing requirement?



There is no additional staffing requirement.

What are the challenges faced by the initiative?



Balancing the focus on preventative initiatives and assessment of patients who may develop significant psychological issues alongside the requirement for psychologists to play a role in managing ongoing mental health issues with the patient and their family, can be time consuming.

What is the impact?



Placing a significant focus on prevention of psychological issues in high-risk patients, represents a more effective and sensitive method of managing a patient's as well as their families' state of mind. This will additionally reinforce the trust built between the patient and the healthcare team.

By managing high-risk patients in this method, psychologists can effectively prevent the occurrence of more serious psychological issues and in so doing free up their time to effectively manage a larger group of patients.

What are the challenges of replicating this?



Other centres must develop a culture of psychological prevention rather than treatment to ensure that the psychologists engage fully in this programme and devote sufficient time and attention towards it.

Casa Hope



Overview

A philanthropic organisation that provides supportive accommodation, transport and facilities for some of ICESPs outpatients and their families.

What is the rationale?



Many patients travel far distances to gain access to the treatment and resources available in Sao Paulo. This means that they do not have accommodation or transport during treatment and when they are discharged as an outpatient, they have no where locally to live so that they can access care. Casa Hope is designed to be seen as a home where patients, donors and their family can live and receive treatment as well as transport to access hospital care when needed.

What are the key features of the initiative?



The house was started in 1996 for children suffering from cancer and their parents.

- 192 beds in the house, these are predominantly paediatric, but there are 68 beds available for adult BMT patients;
- Isolations rooms for those who have multi-resistant bacteria.

Patients are admitted on a first-come, first-serve basis. Casa Hope has relationships with 8 centres, the social workers from each of these centres will call up Casa Hope to see if there is a vacancy. There is a large waiting list due to limited spaces.

Facilities: theatre, classrooms (3 for different age groups), art therapy area, children's playground, baby play area, toddler play area (therapeutic toys); two dining rooms (cancer and then transplant); kitchenettes, basketball/football court; TV rooms (comfortable normal life); transportation (buses, ambulances and removal vans).

Training and education: There is an educational nurse who helps to orientate patients and their family about hygiene and how to take care of themselves (e.g. taking care of catheters etc.).

Support groups: psychologists and social workers run a group for patients and their family teaching them how to deal with the disease and accept treatment work alongside the social worker.

Activities: yoga and other body movement classes; lifestyle courses - run classes to teach parents skills (beauty, cooking and IT), so that once their child is better they can integrate back into the community; celebrations/parties for birthdays.

Partnerships: medical facilities, services and treatment for the patients relatives.

Funding: mainly from two partnerships, state secretary of health and city secretary of health; donations from patients; fundraising events (e.g. dinners, shows/concerts in their theatre; art sales; charity clothes sales; furniture sales).

What is the additional staffing requirement?



Functional staff: Social workers, psychologists, occupational therapists, teachers, finance and marketing.

Auxiliary employees: drivers - own transport and vehicles for: deliveries; hospital trips etc.; laundry; maintenance.

What are the challenges faced by the initiative?



Highly regulated and therefore very bureaucratic procedures required to run effectively.

Maintaining consistent funding to ensure the home is run effectively.

What is the impact?



Giving those patients from lower social-economic backgrounds the ability to access care at ICESP as an outpatient, especially when they have no accommodation, as they have been referred from other states; or when they cannot afford to travel to the hospital to maintain their treatment.

What are the challenges of replicating this?



Ability to provide the resources required to provide supportive housing.

Provision of transport and drivers, for patients.

Access to funding.



Animal-assisted therapy



Overview

A programme aimed at improving the patient's wellbeing by allowing haematological malignancy patients to see their pets, or to interact with dogs in a safe, monitored environment.

What is the rationale?



Being treated for haematological malignancies often results in patients being hospitalised for extended periods of time. In instances where patients have pets with which they have a strong emotional attachment, this hospitalisation period can be mentally difficult. Pet ownership and animal-assisted therapy are strongly correlated to the generation of positive subjective feelings in patients, making them more receptive and trusting of their treating physician and wider stakeholder group.

What are the key features of the initiative?



For patients who request to spend time with their pet during their hospitalisation, there is a strict protocol in place:

- Initially the request must be approved by the treating physician, based on their assessment of the patient health and ability to be involved in this process.
- A vet is engaged to conduct a controlled shower of the animal, and authorise that the animal is in a good state of health (has the correct vaccinations etc.).
- The animal's nails are cut to avoid scratches.
- Patients are dressed in their normal clothing, and are then covered in a protective sheet to avoid contamination.
- The patient is taken in a wheelchair to a closed garden area within the centre, which is dedicated to this activity.
- The patient's family is invited to join in on this activity, all contributing to a positive emotional shift in the patient's mind-set.
- Psychologists are present at all times to assess the interactions.

* Puppies are generally restricted due to their increased activity and associated risk .

The centre also has two 'professional' dogs, providing animal therapy to patients who do not own pets:

- These dogs are hospital employees, and get a salary for B\$1000/month each to support their upkeep.
- They are housed at a not-for-profit organisation with a relationship with ICESP.
- They are brought to the hospital once a month.

What is the additional staffing requirement?



The centre requires a vet on hand to assess and clean the animal prior to its visit to the hospital.

What are the challenges faced by the initiative?



The animal must be assessed by a vet prior to its admittance to the centre. Many patients are from a low socio-economic background conferring that the pet may require some treatment to reach adequate fitness.

The behaviour of the animal must also be assessed to make sure it is suitable. There is a potential risk to property and the surrounding environment, as well as potential risk of injury to the patient.

What is the impact?



There is the significant potential for subjective improvements in the patient's state of mind, with animal-assisted therapy proving to result directly in reduced loneliness, anxiety and fear of patients. This can help build trust between the patient and the haematological malignancy care team, resulting in the patient being more engaged in their treatment and care. Ultimately this can result in improvements in patient outcomes.

What are the challenges of replicating this?



The centre must have a dedicated outside area where the patient can interact with the animal in a controlled environment, away from other patients which may not wish to be around animals.



Patient engagement



Overview

A programme that is run to induct and educate patients around the treatment programme, ensuring they adequately understand and are fully engaged in their treatment.

What is the rationale?



Patients are often unaware of the treatment pathway,

This programme was initiated to help educate patients around the processes involved in the treatment of haematological malignancies. This helps patients to feel more comfortable, understanding the processes and trusting the physicians who will treat them along their journey.

What are the key features of the initiative?



On the first day the patient is with the service:

- 1 person from the MDT presents the institution to the patient (and their family), acting as a host whilst providing the orientation service
 - Explains all of the processes the patient will be subject to (i.e. the expected journey);
 - Discuss some treatments and consequences;
 - Gives full instructions to the patient and their family around care and workings of the hospital.

When the patient begins chemotherapy:

- Host patient groups to discuss the process and aspects of the chemo and answer patient questions.
- There are also individual meetings between the patient and the doctors prior to this nurse led meeting.
- The nurses will explain everything to the patients (e.g. treatment, risks, side effects, future aspects).
- Provides patients with a book with all details they should know.



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Patient workshops:

3 workshops with patients covering a range of aspects including educational workshops:

- One established which aims to teach patients and their families self-care - They have a simulator to allow key care givers to practice protocols (e.g. catheter infection control) which they will be responsible for once the patient is discharged from the inpatient setting.

Patient feedback:

This is requested from patients and their families every month via a survey.

ICESP also conducts face-to-face interviews with some patients to gather their feedback on the care and treatment received while in care.

What is the additional staffing requirement?



No additional staffing requirement.

What are the challenges faced by the initiative?



Development of the programme and logistics of the initiatives need to be coordinated by the admin staff, in lieu of a fully dedicated role for this task. Predominantly these programmes are led by nurses, who have to balance this with their existing role.

What is the impact?



Patients feel more actively engaged in their treatment. They build stronger relationships with the staff involved in their care, trusting them more, which makes them feel more comfortable across the treatment process. Patients who have gone through these groups are more open and are better engaged with their treatment and the physicians involved.

Patients have reduced anxiety and fear. Helps physicians in assessment of the patient as they get to know the patient better.

What are the challenges of replicating this?



Protecting the time of key stakeholders involved in these processes to conduct these activities (e.g. MDT team member for first meeting, nursing staff for feedback interviews etc.).



Group setting support provision



Overview

Group sessions are held for patients and their families to openly discuss the major issues and concerns they have regarding their disease and treatment regimen.

What is the rationale?



Both the patient and their family are exposed to many difficult and emotional situations when treating haematological malignancies. Providing a safe place for patients and their families to openly discuss problems and ask questions, helps to empower patients, allowing them to support each other and benefit from others experiences.

What are the key features of the initiative?



The psychologist is always present during these group sessions - can make assessments on which patients will need more support and target early.

There are two specific group meetings held by ICESP:

1. Support for those near death:
 - MDT meeting held before death to understand the full patient condition;
 - 'During death' - additional support given to patient and the family;
 - Aim to provide comfort, and empathy to patients and family members;
 - Also support the family when asked to identify body following death;
 - Post-death supportive care for the family;
 - Physicians go on a specific two-week training course to help them know how to conduct and deal with 'difficult conversations'.
2. Radiotherapy and Chemotherapy group
 - For patients who go through these for the first time as well as those in relapse;
 - MDT setting for full staff group;
 - Take patients through the treatment/care journey;
 - Discuss side effects and consequences;
 - Answer any questions or doubts (i.e. explains all aspects).

What is the additional staffing requirement?



There are no additional staffing requirements.

What are the challenges faced by the initiative?



Mediation of all patients and family members involved in the group setting may require the attending psychologist to have specific experience in family therapy.

Creation of a safe space where patients and their families feel comfortable enough to share their thoughts, feelings and concerns.

What is the impact?



Patients and their families feel as though they have company, with people who understand what they are going through. Experiences can be shared between patients, easing anxiety and supporting each other.

What are the challenges of replicating this?



Having the time, resource and space to dedicate to these sessions.



We noticed that by doing these group sessions, there is a reduced demand from physicians and their patient's in requesting individualised psychological support.



Psychologist



Patient regulation



Overview

ICESP developed a detailed procedure which was adopted by the State Department of Health to help regulate the diagnosis and centralise patient dissemination across the cities hospitals.

What is the rationale?



Across the public healthcare system, capacity is a universal limiting factor in the ability to deliver good quality care to haematological malignancy patients. It is important that only patients who require treatment from a specialist cancer centre are admitted. The patient regulation initiative exists to validate patient admission to ensure that beds, space and resources are used as effectively as possible.

What are the key features of the initiative?



ICESP developed a screening initiative for patients entering the centre. This was leveraged by the State Secretary of Health to be implemented across all centres in the state. The process of regulation that resulted is:

1. There is a standardised form which all referring physicians must fill out containing information regarding the diagnosis and existing or previous treatments.
2. This form is then submitted to the State Department of Health.
3. These cases are then assessed and confirmed by the physicians within the department (1 physician and 2 nurses).
4. This centralised Department of Health then distributes patients accordingly to centres around the Sao Paulo state, dependent on the patient's location, the diagnosis and the availability capacity of specialist centres.
3. When a patient is referred by this department to ICESP, the patient regulation team at ICESP double check the diagnosis before the patient is admitted and the treatment initiated.

Prior to state adoption the standardised form was approved by all the main centres in the region. Any additional suggestions and comments were added in order to validate the criteria.

The State Secretary of Health has a meeting once a month with all centres involved in the system to understand their current capacity issues, to allow it to plan for referrals.



Hospitals are able to reject patients on capacity grounds, following which the State Secretary for Health referred the patient to another suitable hospital in order to receive treatment sooner.

What is the additional staffing requirement?



Patient regulation team (consisting of admin staff and nurses).

What are the challenges faced by the initiative?



Gaining consensus of the referral requirements across all of the centres within the network is essential to ensuring effective implementation of the regulatory process. Integrating service delivery with primary and secondary healthcare settings to reduce time-to-diagnosis and time-to-treatment.

What is the impact?



This programme has helped to release capacity and time of treating physicians, who used to be responsible for confirming diagnoses and coordinating patient movement through the system. Physicians are now able to devote more time to treating patients.

Due to the level of checks conducted between the referring physician and the treatment initiation, misdiagnosis levels are very low.

What are the challenges of replicating this?



This initiative relies on centres establishing a robust network of communication to ensure that they work effectively together to deliver good quality care and management to patients with haematological malignancies. Additionally this requires strong communication channels and deep integration with primary and secondary care centres from which patients are diagnosed/referred.



Clinica Colombia Colsanitas

Department of Haematology

Bogotá, Colombia

—

KPMG, December 2017





Clinica Colombia aims to provide fully integrated care for haematological malignancy patients across the entire patient pathway

Key findings from the centre



Strong array of diagnostic and prognostic facilities in house

- The centre is capable of carrying out essential diagnostic procedures for haematological malignancy such as flow cytometry, FISH, immunohistochemistry, pathology etc. Additionally the centre has facilities to perform some advanced techniques such as next-generation sequencing, used to provide prognostic/risk stratification indicators for inpatients.

Robust linkage to care pathway to ensure patients enter treatment as soon as possible

- The investigation laboratories at Clinica Colombia are part of a wider centralised laboratory network within the country. These receive samples from primary and secondary medical centres nationally and provide results, with a system of automated and defined alarms directing the patient into the care pathway as soon as possible, should abnormalities be detected.

Multi-disciplinary team structure to inform and validate patient management

- All of the key stakeholders in the care and management of haematological malignancy patients are involved in regular formal MDT meetings, discussing difficult case management, current treatment paradigms and guidelines, incorporation of new drugs into formularies, inter-departmental relationships and operational processes (e.g. ICU coordination), etc.

Oncology route project to closely monitor passage through the care pathway

- A dedicated programme designed to standardise and optimise the operational aspects of a patient's journey through their disease, from ensuring rapid diagnosis and linkage to care, to having a robust process to monitor patient progress in the follow-up phase once they have left the hospital, in an effort to prevent the patient being lost from the system.

Key challenges faced in the delivery of haematological malignancy care



Highly-fragmented care system

- Outside of the Colsanitas network, the healthcare system in Colombia is highly fragmented, causing significant delays to patients in terms of key outcomes such as 'time to diagnosis' and 'time to treatment'. Sharing of data between different institutes and stages of care is complex/incomplete and time consuming.

Lack of guidelines specific to Colombia

- Due to the lack of national guidelines for many disorders, there are significant inconsistencies between treatment regimens. Additionally those guidelines that are published internationally are not specific to the Colombian population meaning that outcomes from treatments can vary from those expected, and that drugs recommended may not be available through the Colombian healthcare system.

Administrative burden on patients is considerable

- Due to the complex administrative requirements on patients in order to access care, many hospitals fail to meet their time-dependent targets for patients linkage to care/treatment, and patients risk being lost from the system entirely in some cases.



Clinica Colombia is a highly-specialised centre offering diagnosis and treatment to patients from across the country

Haematological malignancy specialty unit



Services: Clinica Colombia provides the full range of integrated services to haematological malignancy patients in a centralised fashion, with the current exception of bone marrow transplant. It is currently working closely with ASH to become recognised as an ASH Centre of Excellence.

Resources: The hospital is currently laid out over two adjacent buildings, one predominantly for outpatients and one for inpatients.

Teaching: Numerous residency and training programmes across key specialities are provided. There is a large programme of training in pathology/haemato-pathology, for which residents are received from over 20 different universities in Colombia.

Collaborations: Engages with all other centres within the Sanitas group to support patient care and management. Works closely with patient association groups to support patients and their families through their disease.

Funding: Clinica Colombia is part of the Colsanitas group from which it receives the majority of its funding. The healthcare provider (Sanitas EPS) is also part of the group resulting in a highly unique circumstance.

Haematologist(s): Five haematologists;
Two haemato-pathologists.

The patients



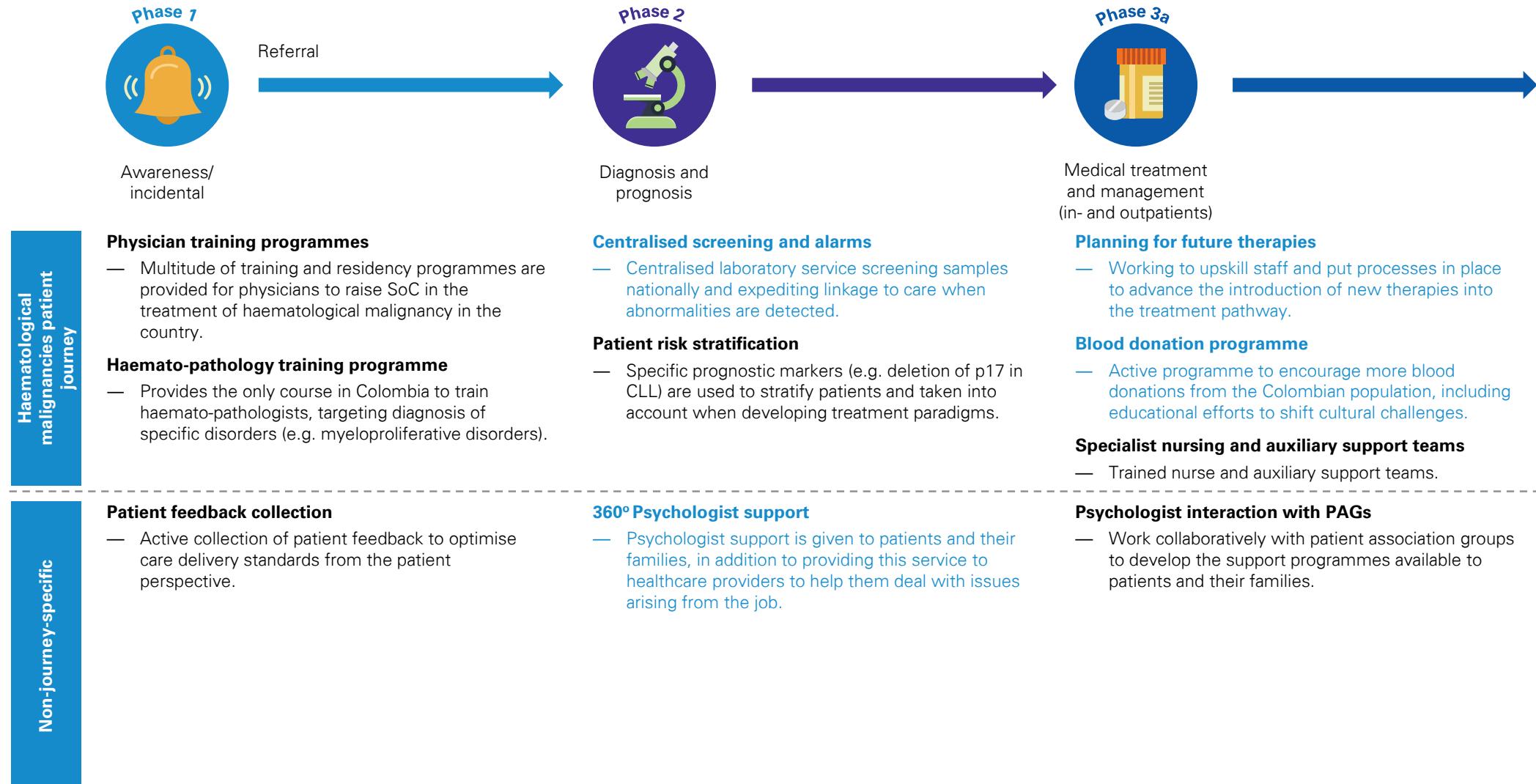
Geographic scope: Receive patients from all over Colombia, predominantly from referral from within the Sanitas group.

Patient population: Referred patients (adult and paediatric patients) from the primary/secondary care setting. Most patients have private healthcare coverage under the Sanitas group.

Number of patients: Sanitas EPS (the healthcare provider of the same group) had >500,000 new patients last year.



The unit has established a number of initiatives to improve patient care





Blue text = Case study available



Phase 3b
Bone marrow
transplantation



Phase 3c
Monitoring and
follow-up



Phase 4
Palliative care

Fertility preservation programme

- Programme to help younger patients with haematological malignancy to preserve the chance of bearing children after their treatment.

T-cell Registry project

- Programme to establish a national registry with accurate data to track patients and develop clarity of disease prevalence in the country.

Oncology route programme

- Programme to standardise and optimise the processes behind linkage to care and follow-up after treatment.

Pharmacy drug validation

- Standardised checklist to ensure all drugs received from supplier are of high-quality and suitable for use in patients.

Infection control programmes

- Nurse-led infection control programme where training is provided to physicians, patients and families on hygiene (e.g. handwashing). Nurse team observes at randomly selected times, and tracks on database. Plans to link to outcomes (e.g. antibiotic use).



Summary

A highly integrated team across all specialities is responsible for delivering care to patients with haematological malignancy

Key features of the HM care delivery team:



- A highly-specialised multi-disciplinary care team dedicated to delivering fully integrated care to patients with haematological malignancy.
- In-house access to a wide variety of diagnostic and prognostic facilities, with more advanced techniques such as next-generation sequencing available to inpatients.
- Specialist haemato-oncology nurses who are trained to coordinate and administer chemotherapy related processes including basic invasive procedures.
- Regular training for all key specialists, and the only site in Colombia to offer specific training for haemato-pathologists.
- Close, daily interaction with ICU team to ensure high-quality management of haematological malignancy patients with intensive care requirements.
- Psychological support team is available to patients and their families, in addition to being available to the healthcare professionals.
- Dedicated staff to monitor and coordinate linkage to care and follow-up of patients to ensure patients are not lost from the system (i.e. oncology route programme).
- Dedicated palliative care team which works closely with psychology staff to support patients and their families throughout the end-of-life stage.
- Dedicated rehabilitation team and facilities, to ensure that patients hospitalised for prolonged periods of time remain active to the benefit of their treatment and health.



Governance and processes



Team meetings:

Multiple multi-disciplinary team meetings covering aspects such as difficult case management, current treatment paradigms and guidelines, incorporation of new drugs into formularies, inter-departmental relationships and operational processes.

Patient records:

All patient records are recorded on a fully integrated electronic platform to which all healthcare professionals have access (varying degrees depending on position/role).

Pharmacy:

Work with the distributor Cruz Verde to acquire medication for treatment. The pharmacy follows a strict checklist to ensure all received materials arrive in good quality, and work closely with the care team to validate prescriptions.

The patient is the priority; they are not just a number.

Head, Haemato-oncology





How can haematological malignancy care be improved?

What is next for the centre?



Oncology day clinic

Outpatient care for extended chemotherapy administration is not the norm in Colombia. Clinica Colombia is looking to establish a day clinic for patients who are undergoing chemotherapy, where they will be able to receive their treatment without the need for extended hospitalisation. This unit will also be able to perform related procedures such as transfusions, management of reactions etc. The benefits of being able to do this in the day clinic setting would be reduced financial burden on the hospital due to hospitalisation, faster access to treatment for patients due to the reduced need to wait for bed availability, and consequently better patient outcomes.

Bone marrow transplant unit

While Clinica Colombia has most of the capabilities and facilities required to meet its goal of offering fully integrated care across the full patient pathway, the one large omission is a bone marrow transplant unit. Currently patients are transferred to another facility in Bogotá to receive this treatment, which results in long waiting times and reduction in treatment efficacy. Clinica Colombia aims to offer autologous stem cell transplant initially, but to gradually expand to include allogenic and haplo-identical transplants. This will additionally ensure continuity of care as the treating physician at Clinica Colombia will remain involved in the care throughout the process.

Home care provision

Clinica Colombia plans to eventually offer the provision for care delivery in patient's homes. Processes that could be conducted in this environment could include sampling for simple tests (e.g. bloods), administration of antibiotics under supervision etc. This would likely require patients to have a high level of coverage. Benefits of this service would be a decrease in the number of hospitalised days, correlating with reduced patient burden and reduced hospital spend and optimisation of hospital resource usage.

Internal medicine as treating physician

In the future, Clinica Colombia aims to upskill internal medicine physicians to the point that they are able to occupy the role of main physician for haematological malignancy patients. This will allow haematologists to occupy a dynamic role between patients, providing advice and direct care linked solely to the haematological malignancy. In this model, patients would benefit from the integral perspective given to their health by the internal medicine physician. This would additionally serve to alleviate the capacity crisis on haematologists time, allowing more patients with haematological malignancy to be treated.

What advice would you give to less-specialised centres?



Identify patients as early as possible Setting in place a process (e.g. linking with diagnostic laboratories in other cities to create a system of early warning) can enable patients to be identified as early as possible, which can have a significant impact on clinical outcomes.

Set in place a robust patient follow-up To ensure continuity of care it is important to follow-up patients at regular intervals, keeping track of their well-being. This enables relapses to be identified and managed in a timely manner.



Case studies



Centralised screening and alarms



Overview

A defined and automated set of alarms based on evidence-backed criteria, that are applied to the results of centralised laboratory tests, ensuring that linkage to care is robust and rapid for potential patients across the country.

What is the rationale?



Linkage to care is one of the key challenges in the treatment of patients with haematological malignancy in Latin America. Only a small proportion of the country has facilities and capabilities which are able to analyse samples and produce reliable diagnoses (i.e. major cities, such as Bogotá). As such, a system is required to extend the reach of these facilities beyond the few cities which have them, and to ensure that identification of disease and initiation of the processes required to get patients into care is not wholly dependent on highly-time-constrained staff.

What are the key features of the initiative?



The diagnostic and prognostic laboratories in Clinica Colombia operate as part of a larger centralised laboratory network, which receives samples from primary and secondary care centres from across the country, both from within the Colsanitas group, and from external institutions. This works to concentrate the performance of many key tests, expanding the reach of the facilities available.

A robust series of evidence-supported 'alarms' are built into the standardised processes of the laboratories. The clinical parameters to which these alarms are set are defined by the WHO/American Haematology Society guidelines.

Key advantages are:

- All blood films from across the country are able to be reviewed by a haemato-pathologist.
- Technician or software is able to make the initial finding, and then refer suspected cases to the haemato-pathologist, reducing the burden on the haemato-pathologist.

- If abnormality is detected, the patient is contacted directly and told to contact their location physician to progress to treatment. A haematologist appointment can also be immediately established ensuring time to full diagnosis and treatment is expedited.

What is the additional staffing requirement?



Enough trained technicians to conduct initial screening tests, and trained haemato-pathologists to review suspected cases to confirm diagnosis.

What are the challenges faced by the initiative?



Ensuring that following contact, the patient is able to get in contact and attend local consultations if not directly referred to a reference centre haematologist.

What is the impact?



Patients are linked to care much sooner than they would be without this system, and important metrics such as time-to-diagnosis and time-to-treatment are reduced in a manner not dependent on the location of the patient.

What are the challenges of replicating this?



The establishment of the infrastructure required to replicate this system:

- A centralised laboratory system is required to ensure all patients nationally benefit from the facilities and experience of centres in major cities.
- Time to define criteria to build alarm system.



We do our best to catch all patients. Even if they are at home, and how they can be seen quickly.



Haemato-pathologist



Planning for future therapies



Overview

Clinica Colombia haematologists have identified the newly approved (in the US) CAR-T therapy as being potentially highly beneficial to patients, and are designing a roadmap for its implementation into treatment paradigms at the centre by 2020.

What is the rationale?



The identification and incorporation of new therapies and technologies into the routine treatment paradigm for patients can be a lengthy process. The effort to identify therapies, upskill staff and prepare resources ahead of time can expedite this process, bringing the benefit to patients sooner. Currently there is no location in Colombia with the facilities and experience required to deliver these treatments.

What are the key features of the initiative?



Haematologists at the centre are planning to incorporate novel, advanced cell therapies into the treatment paradigm for patients with relevant haematological malignancies by 2020. To ensure this plan is effected, they are taking a number of approaches to ensure the hospital is ready for the future availability of novel advanced cell therapies (e.g. CAR-T therapy) to patients in Colombia. Examples of such actions include:

- Actively seeking out and engaging with other centres globally that are pioneering these new treatments. This ensures that physicians are able to gain experience with delivering these new therapies to patients, and managing aspects associated with their usage.
- Leveraging suitable national and regional platforms to advocate for the approval and use of novel advanced cell therapies in the region as often as possible over the coming years.

What is the additional staffing requirement?



No additional resources required at early stages. Building relationships with pioneering centres globally will help to gain knowledge of future therapies and consequently time will be required to upskill staff.

What are the challenges faced by the initiative?



Identifying and obtaining suitable opportunities to gain experience with novel technologies ahead of national approval.

What is the impact?



Bringing novel advanced cell therapies to patients earlier will permit patients to benefit from the improved patient outcomes associated with these therapies compared with the outcomes associated with the existing available therapies for haematological malignancies.

What are the challenges of replicating this?



Time required to educate staff.

Relationships to permit access to use of novel therapies ahead of Colombian approval to allow physicians to gain experience in their use.



Types of advanced cell therapies, directed therapies will eventually replace transplants. We need to be ready.



Haematologist

Blood donation programme



Overview

A programme run by Clinica Colombia to actively encourage more blood donations from the Colombian population, including educational efforts to shift cultural challenges which are perceived as a barrier to donation.

What is the rationale?



There are currently not enough blood donations in Colombia to meet the national requirements. As a direct consequence of this, centres such as Clinica Colombia regularly have to purchase additional blood supplies from organisations such as the Red Cross, reducing the budget for spending elsewhere in the system. Consequently by driving the increased donation of blood, the institute hopes to be better able to meet the needs of its population and thus treat more patients with fewer costs.

What are the key features of the initiative?



There are a number of different mechanisms employed by Clinica Colombia in an effort to increase the number of blood donations received from the Colombian public.

- National campaigns are run to increase the awareness of the population to the need for blood donations by the healthcare system.
- Clinica Colombia run a number of mobile blood collection units, ensuring that those who want to give blood but who are unable to come into a hospital are able to donate.
- The hospital also produces a series of educational materials, aimed at overcoming the barrier to donation represented by misinformation and existing cultural beliefs surrounding blood donation that exist in the population. This is general distributed to patients families and friends during the course of the patients stay in hospital.

What is the additional staffing requirement?



Staff educated to designing and running any blood donation campaigns in the community.

Staff to run the mobile units to promote blood donation in the community setting.

Staff responsible for producing educational materials for friends and families to promote blood donation.

What are the challenges faced by the initiative?



A key challenge to driving the increased donation of blood by members of the community lies in the cultural beliefs of the population, which do not view blood donation favourably. Additionally potential donors may be spread over large areas, with limited access to the hospital, putting significant stress on the capacity offered by mobile units.

What is the impact?



Patients will benefit from having blood available to support any initiatives necessary, as supply gains parity with demand for blood products. Additionally this will benefit the centre financially, as there will be a reduced need to procure blood products from other parties, such as the Red Cross.

What are the challenges of replicating this?



Production of educational materials for the population that resonate with their cultural beliefs and social situation.

Procurement of facilities required to offer mobile blood donation services.



360 degree psychologist support



Overview

Psychologist support is offered to patients and their families, to help them manage their mental state throughout the course of their disease. In addition, these services are offered to healthcare providers to help them deal with issues arising from the job.

What is the rationale?



Due to the nature of haematological malignancy and the timeline associated with its treatment, the effective management of the social and mental aspects of the disease, on both the patient and their family, is essential to ensuring good patient outcomes. In addition, due to the serious, and often terminal nature of the disease, it is essential that the staff involved in caring for and treating patients, are also supported with any mental or social issues they become burdened with.

What are the key features of the initiative?



Patient and family support is offered to both inpatient and outpatients at the centre:

- The psychology team has developed their own questionnaire to assess the mental states of patients and their families, which is validated specifically in the Colombian population.
 - This was developed due to the lack of existing tools;
 - Its development was supported by a review of the relevant literature;
 - The questionnaire covers all aspects of the patient journey, in addition to patient-centric metrics such as Quality of Life.
- All patients entering the hospital system receive an initial psychological assessment, and patients due to receive chemotherapy are all assessed on the day prior to the administration of the treatment.

There is currently no formal support available to healthcare staff, however ad hoc meetings, as requested by the healthcare staff member, can be established if support is required:

- The centre is currently developing a group therapy setting to support staff.

What is the additional staffing requirement?



A trained team of psychologists, familiar with, or specialised to work with, patients with haematological malignancy.

What are the challenges faced by the initiative?



Managing patients and their families who are often highly stressed or angry is a challenge, and requires a significant time investment from the psychology team. Also understanding what outcomes or metrics to measure in order to quantify the benefits psychological support represent remains a significant challenge.

What is the impact?



Patients and their families benefit from a better mental state, which helps them to manage their disease better. Healthcare staff feel emotionally supported by the centre, and have a reduced risk of burnout. Physicians are also better able to understand the patient, and can design a treatment plan in line with this improved understanding.

What are the challenges of replicating this?



Time and resourcing required to provide this support to patient and their families, as well as members of the healthcare team.



We want to know every patient all the time, and their families too.



Psychologist



Oncology route programme



Overview

Programme to standardise and optimise the processes behind linkage to care and follow-up after treatment, ensuring that patients receive care as soon as possible, and that once discharged, they are not lost from the system. This programme was conceived to meet the requirements of new legislation in Colombia (UFCA).

What is the rationale?



Currently in Colombia there is a delay in patients being presented to a suitable, specialised haematology service when they develop a haematological malignancy. Additionally, when patients are discharged from a haematology service, monitoring and follow-up procedures are not as robust they could ideally be. The impact of this is that patient outcomes are worse than they could be due to late onset of treatment, and that relapse and secondary malignancies are not detected in a timely manner. This programme seeks to optimise and standardise linkage to care and monitoring and follow-up in an effort to reduce patient outcomes across the disease pathway.

What are the key features of the initiative?



This initiative is made possible by the existing infrastructure and qualifications/skills of the stakeholders involved, which previously had been under-leveraged:

- There are six people with the dedicated role of coordinating the logistics of the programme.
- The service is under the management of the Chief of Haematology.

The programme has set a number of defined outcomes which represent success:

1. <30 days from presentation to diagnosis;
2. <30 days from diagnosis to the onset of treatment (if indicated);
3. <30 days from request to the delivery of radiotherapy.



There is currently no formal support available to healthcare staff, however ad hoc meetings, as requested by the healthcare staff member, can be established if support is required:

- The centre is currently developing a group therapy setting to support staff.

What is the additional staffing requirement?



Staff personnel required to run the logistics of the programme.

What are the challenges faced by the initiative?



Ensuring the programme reaches 100% coverage of the diagnosed cancer population. Coordination of the vast number of patients within the programme effectively and accurately (there are almost 8000 patients under the Colsanitas EPS; currently only ~1400 are captured within the programme).

There is no consolidated single source of information for all patients nationally. Securing the capacity and personnel to run the programme effectively (e.g. there is a small window of time when a patient should be transferred for treatment which requires the availability of haematologists, beds, treatment room/spaces etc.).

What is the impact?



By ensuring patients are linked to care and treatment as soon as possible, and by ensuring they are correctly followed up, all patient outcomes will be improved, and wastage in the system, due to failed treatment runs etc. will be reduced.

What are the challenges of replicating this?



Staff and resource requirement to run the programme.

Gaining participation from all centres across the targeted region.

Correctly establishing the standardised service across a large number of disconnected centres.

**Our aim is to not lose a single patient.
Haematology nurse**



Fundación Santa Fe de Bogotá (FSFB)

Bogota, Colombia

—

KPMG, November 2017





Fundación Santa Fe de Bogotá (FSFB) has implemented multiple quality control initiatives to measure performance

Key findings from the centre



Highly-specialised team involved in the management of haematological malignancies

- FSFB has a highly-specialised multi-disciplinary team that collaborates in the delivery of patient care. The creation of a Multiple Myeloma Excellence Group is underway, with the aim of establishing a JCI-accredited world leading centre for management of multiple myeloma.

Strong focus on quality control

- In depth databases (managed by the nursing team) are in place to capture outcomes data on various elements of patient care, (e.g. BMT or outpatient unit). The outcomes from this programme are fed back to the respective teams and discussed in regular meetings.

Dedicated physician team

- All the physicians working at FSFB are full-time employees of the foundation, meaning that they do not share their time across other institutions. This allows them to integrate better into the hospital setting and get to know their team and patients in a deeper fashion.

Efforts to track quality outcomes

- The quality team collects outcomes and analysed them weekly to review the effectiveness of care delivery across the patient journey; examples of indicators tracked include mortality following relapse, mortality following transplant, adherence of physicians to established protocols at different stages of patient care etc.

Key challenges faced in the delivery of haematological malignancy care



Improved integrated and patient-centric care

- While there is an effort to deliver integrated care to patients, there is room for improvement by bringing together interdisciplinary teams including specialists nurses to provide personalised and patient centric care.

Low number of haemato-pathologists

- There is a shortage of haemato-pathologists, with only 10 specialists available in the country, which results in delays or misdiagnosis of haematological malignancy conditions.

Changing policies of Health Maintenance Organisations (HMOs)

- Frequently changing policies of the HMOs may result in patient being lost to the system, as patients may be moved to different hospitals. This also results in the loss of continuity of care, adversely impacting the patient experience and possibly patient treatment outcomes.

Health insurance does not cover all diagnostic exams

- Diagnosis is seen as a key challenge in Colombia, and even in the private care setting (as in FSFB), health insurers do not cover use of all diagnostic examinations that may be required to produce a robust diagnosis and prognosis. This potentially impacts the physicians ability to provide the highest quality care to patients, and thus impacting their treatment outcomes.



FSFB is a fourth level medical care facility, managing highly complex conditions

Haematological malignancy specialty unit



Services: Not-for-profit organisation providing medical care to patients with specialised insurance coverage.

Resources: 300 (in- and outpatient) beds, of which ~90 are ICU.

Teaching: Several training programmes, including seminars open to the public for education on palliative care.

Collaborations: Multiple collaborations, including international agreements, e.g. with Johns Hopkins and Mayo Clinic, USA.

Funding: Not-for-profit organisation.

The patients

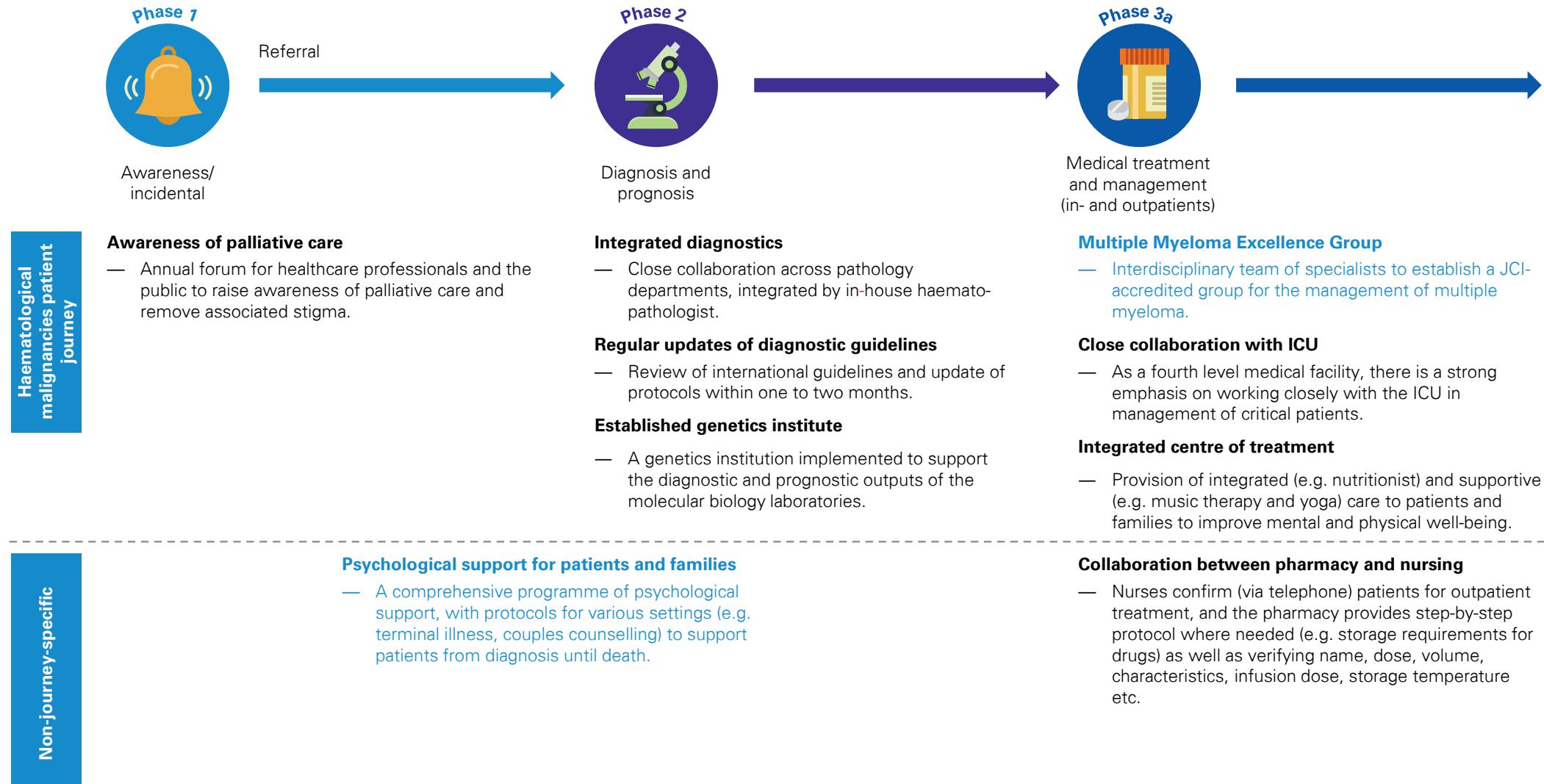


Geographic scope: Bogota and the surrounding area.

Patient population: Adult and paediatric patients with private insurance cover (8-10 specific insurance providers are contracted with FSFB as of November 2017).



They have established a number of initiatives to improve patient care





Blue text = Case study available



Phase 3b
Bone marrow transplantation



Phase 3c
Monitoring and follow-up



Phase 4
Palliative care

Nurse-led transplant quality control programme

- Close monitoring of various outcomes data to monitor and measure performance of the BMT unit.

Day clinic for non-emergency interventions

- Established a day clinic to manage non-emergency interventions for patients not requiring admittance to hospital, including those patients eligible for chemotherapy and simple interventions in an outpatient setting.

Comprehensive palliative care programme

- In-patient and at-home palliative care offered to patients through a highly-specialised team.

Euthanasia protocol

- Well-designed and rigorous euthanasia protocol in place for assistance of patients.

Electronic patient and family education materials

- Educational materials have been produced for patients and their families, to cover some of the important corresponding topics related to the disease which the haematologists may not have time to cover (e.g. nutrition, sexual health etc.).
- There are quizzes at the end of each topic to measure the recipients understanding.

Quality team

- A dedicated quality team working across all the individual specialities, who are in charge of aligning and verifying the processes, guidelines and protocols required to deliver good quality care
- Meetings are held with specialities to review collected data and highlight improvement areas



Our work starts when the patient is diagnosed and ends when the patient dies. We aim to offer a fully integrated service.



Haematologist



Summary

A highly-specialised team is available for close patient management

Key features of the HM care delivery team:



- A specialised group of haematologists who work closely together. They are full-time employees of FSFB, and therefore do not share their time across multiple institutions.
- Emphasis on the treatment of multiple myeloma (MM), with a group established with the aim of becoming a reference centre for this indication globally.
- Specialise nurse team, trained on-site, in oncology and transplant, who lead on patient management and quality control.
- In-house haemato-pathologist, with integrated diagnostic services to provide rapid results.
- Very close collaboration between haematology and the ICU to ensure rapid transfer of patients when needed.
- Comprehensive psychology support programme, with protocols for multiple settings (e.g. couple therapy).
- Fully integrated palliative care programme, delivering care to patients both within the hospital and at home.

Governance and processes



Team meetings:

Regular meeting of haematology team to discuss complex cases held every Thursday. A Multiple Myeloma Excellence Group has been established to specialise in this indication.

Patient records:

Patients records are all stored electronically within FSFB.

Pharmacy:

Integrated pharmacy service, working closely with nurse practitioners to ensure provision of medication.



How can haematological malignancy care be improved?

What is next for the centre?



Establishment of a centre of excellence for Myeloma

FSFB is aiming to bring together the Multiple Myeloma excellence group and all required facilities into one unit to form a fully integrated centre of excellence focusing on the care and management of patients with Multiple Myeloma.

What advice would you give to less-specialised centres?



Cultivate a strong team mentality Bringing together multiple disciplines and ensuring coherent working groups, where each member understands the importance of their contribution is critical for optimal patient management. This is particularly true in the case of highly complex patients.

Track outcomes to measure quality Identifying key performance indicators for specific steps of the patient journey (e.g. transplant), and implementing processes for capturing outcomes, and implementing required changes is critical for maintaining the provision of high-quality care.



Case Studies



Psychological support for patients and families



Overview

A comprehensive programme of psychological support to patients and care givers, initiated at diagnosis and continued until patient death

What is the rationale?



Haematological malignancies can have significant impact on the mental well-being of both patients and their care givers, requiring regular engagement with a psychologist. The needs of the patients at various stages of the journey may be different, thereby requiring specialised interventions at each stage.

What are the key features of the initiative?



The psychology team at FSFB have well-established protocols in place to manage patients and caregivers across the patient journey. Support is offered at patient or consultant request. Current protocols cover various aspects including:

- Family support including support for children;
- Couple therapy;
- High-risk group therapy (e.g. substance abuse or suicide risk).

Several protocols (e.g. one of HADs) has been validated in house using small scale clinical trials.

The psychology team uses multi-channel communication methods to engage with patients, even at discharge. This includes the use of social media (e.g. Instagram, Facebook, twitter, skype). This enables the psychology team to understand the patient in their own environment. This is particularly relevant for younger people as they may express themselves better through social media.

What is the additional staffing requirement?



Dedicated psychologist and support team.

What are the challenges faced by the initiative?



There is a reluctance or stigma against seeking support from a psychologist, based on the poor perception of the value of psychological interventions. This is addressed by providing psychoeducation for the patients, as well as adapting relevant protocols to suit Colombian populations (e.g. primarily from Spain or Mexico as these are developed to align with similar cultural beliefs).

What is the impact?



Improved mental well-being of patients and their carers, who are supported throughout the entire journey.

What are the challenges of replicating this?



Specialist team with resources to adapt and trial protocols and develop initiatives.



Use of social media is an important way to communicate with patients, especially the younger ones, who may prefer or be able to express themselves better this way. It provides a chance to get to know the patient much better, learn about their environment and the support systems they have in place.



Psychologist



Multiple Myeloma Excellence Group



Overview

A highly-specialised interdisciplinary group focusing on multiple myeloma, with the aim of creating a JCI-accredited Centre of Excellence for its management.

What is the rationale?



The challenges in management of multiple myeloma has changed over the recent years, moving from a condition of low survival to that of a chronic condition, with improvements in overall and progression-free survival. However, treatment of this condition continues to be highly heterogeneous across the country, and there is greater need for integrated, patient-centric and specialised care.

What are the key features of the initiative?



A multi-disciplinary group focused on management of multiple myeloma (MM).

Format:

- Multidisciplinary group of specialists consisting of haematologists, haematopathologists, radiotherapy, nuclear medicine, pathology, laboratory teams and others (e.g. orthopaedics, nephrology, neurology etc.) where required.
- Weekly meetings to discuss all new patients, complex cases and plans for JCI-accreditation as a centre specialising in MM.
- Several ongoing studies for assessment of outcomes, including retrospective analysis of own database of myeloma outcomes (35 years of records).

Aim:

- Adapt guidelines (e.g. IMWG) to suit Colombian requirements.
- Undertake trials to assess impact of interventions, (e.g. MM patient education on treatment adherence, Quality of Life and overall survival rate).
- Analyse and publish findings (from MM patient database with data from over 35 years).
- Become a reference centre in Latin America for management of MM.

What is the additional staffing requirement?



Dedicated time from MDT.

Group coordinated by two haematologists, two radiotherapists, one nuclear medicine and one quality control.

Two haematologists coordinate patient education trial.

What are the challenges faced by the initiative?



Ensuring a 'group thinking' mentality and protecting the time, of already very busy physicians, to dedicate towards setting up a group; this can be overcome by persistent demonstration of the potential impact of forming the group, with protected time for certain activities, such as research.

What is the impact?



The aim is to provide high-quality diagnostics and treatment to MM patients, with protocols that have been tested within the Colombian population.

There are already a number of changes to first-line treatment protocols have been made to existing protocols in response to ongoing analysis.

What are the challenges of replicating this?



Time and resource dedication to material development.

Development and tracking of metrics in order to measure impact.



You have to fight for every member to understand the importance of what they are doing, and that they are a critical member of the team. So you have to sustain the enthusiasm even when it is hard.



Haematologist



Nurse-led transplant quality control programme



Overview

Defined set of metrics for quality control post-transplant, that are monitored and analysed by dedicated team members.

What is the rationale?



Transplants continue to be the cornerstone for the treatment of haematology malignancies, therefore clear process and metrics for measuring outcomes are crucial in measuring the success of the intervention.

What are the key features of the intervention?



A well-designed process for managing quality of transplants performed in-house, led by specialised BMT nurses, who have been trained in-house:

Patient education sessions: nurses meet all patients (and their families) approved for transplant, and provide information such as step-by-step explanations of the procedure, possible symptoms and adverse events.

Regular patient contact: phone numbers are shared with patients and families to ensure contact is possible at any time.

Collection of quantitative metrics: a comprehensive set of outcomes are collected on a regular basis. Data is analysed monthly by the nurses and any changes are fed back to the care delivery teams.

- Post-transplant complications (e.g. hypokalaemia);
- Overall survival (post-transplant) at 100 and 360 days;
- Mortality related to transplant;
- Physician adherence to protocols.

Robust follow-up: nurses call patients at each of the follow-up points (e.g. 15, 30 days post-transplant).

What is the additional staffing requirement?



Dedicated time from the nurse or admin teams to capture and analyse data.

What are the challenges faced by the initiative?



Ensuring that data is collected regularly and comprehensively and that it is correctly and analysed, with prompt action taking place to address any highlighted problems. This is managed by having a dedicated nurse team who manage the transplant patients and the database.

What is the impact?



Improved patient safety.

Improved quality of procedures and outcomes.

What are the challenges of replicating this?



Dedicated care team resource requirement.

Database and other supporting infrastructure to manage the data collection and analysis.



Nurses working in BMT are specialised, they receive training in hospital, and require to have participated in six procedures before they are considered specialised.



Specialist nurse



Specialised palliative care unit



Overview

A dedicated palliative care unit that provides comprehensive support to patients across the entire journey.

What is the rationale?



Palliative care is a critical component of haematological malignancy management. Earlier intervention of the palliative care speciality has been recommended in order to implement optimal patient care. A specialised team is required to manage this service both in hospital and in the community, these include symptoms (e.g. pain), patient and family education and interventions.

What are the key features of the intervention?



The palliative care unit works closely with haematological malignancy patients, getting involved in patient care as early as diagnosis, depending on consulting physician preference.

There are two permanent palliative care specialists in the team, a specialist who works part-time (geriatrics and internal medicine) and a specialist palliative care nurse. Services are required to be covered by the patient themselves (some elements may be included in insurance schemes that patients are a part of). Support can be provided in hospital or at patient's home.

An education programme is in place to inform patients/families and other healthcare professionals on the use of palliative care, and attempt to remove some of the surrounding stigma, e.g.:

- Annual symposium (for physicians/public) on palliative care.
- Formal education with patient/families: what to do/not to do, nutrition, end of life care (including psychological support).

Other features:

- Email and telephone access for palliative care services.
- Plan to establish a hospice for terminally ill patients who may prefer to stay in hospital until the end.

What is the additional staffing requirement?



Funding for dedicated team of specialists.

What are the challenges faced by the initiative?



Managing the families' ability to deal with death (including questions of euthanasia) has been a key challenge. This has been addressed through the development of comprehensive patient and physician education programmes providing information around the topic.

What is the impact?



Greater support for patients and families at end of life leading to greater patient and family satisfaction with their care.

What are the challenges of replicating this?



Funding for dedicated palliative care team.

Availability of facilities and the premises to deliver this care (e.g. space for hospice).



We are working to integrate palliative care services earlier into the patient journey. Key is to start having conversations with haematologists and oncologists as early as possible.



Palliative care specialist



Euthanasia programme



Overview

Legalisation of euthanasia in Colombia has meant a well-designed and rigorous protocols are required to manage patients who require this option, and to optimise processes for its implementation.

What is the rationale?



Since the legalisation of euthanasia in Colombia, 20 official cases have taken place, seven of which have been at FSFB. A rigorous process is required to ensure patient safety and Quality of Life is focal throughout; and that quality control of the process is maintained with adequate support of the physicians and nurses who take part in the process.

What are the key features of the initiative?



The legalisation of euthanasia in Colombia has resulted in the need for a well-designed and rigorous process for its implementation. At FSFB, euthanasia is offered only to those who have been in-patients at the hospital.

Key features include:

- A special committee formed when euthanasia is requested, consisting of a euthanasia specialist, psychiatrist, palliative care specialists, Institute Director and a 'pair' of haematologists, i.e. treating physician and a second independent .
- A formal meeting is held, where all options available to the patient are discussed. If decision to proceed with euthanasia is agreed then a 'Euthanasia Group' is formed.
- The 'Euthanasia Group' will comprise several specialists, including several doctors, nurses and the Institute Director – who all enter and leave the patient's room as a group. No one outside the room knows which of the group performed the procedure, which protects the healthcare professionals from any stigma associated with carrying out the procedure.
- The whole process is formally documented.

What is the additional staffing requirement?



No additional staffing requirement, development of a process is required.

What are the challenges faced by the initiative?



Setting up a process that ensuring patients and physician safety; addressed by developing a carefully controlled, collaborative process that is quality controlled at each step.

What is the impact?



Safety and dignity for patients and families who opt for euthanasia.

Safety and well-being of the healthcare professionals who participate in the process.

What are the challenges of replicating this?



Development of a rigorous process supported by defined protocols.

Creating education and buy-in from physicians to participate.



We are proud of our well-designed and rigorous programme for offering euthanasia to patients.



Director





Instituto Nacional de Cancerología (INCan)

Department of Haematology

Ciudad de Mexico, Mexico

—
KPMG, July 2017





A leading centre in Mexico for the provision of haematological malignancy care

Key findings from the centre



Purpose-built infrastructure

- The newly-developed INCan buildings and available technologies (e.g. eight linear accelerators, two PET scanners) provide a highly-sophisticated tertiary care environment for patients with haematological malignancies across the entire patient pathway.

Strong diagnostic capabilities in-house

- Specialised diagnostic capabilities, including cytogenetics, flow cytometry and molecular biology to support rapid diagnosis in-house. This is further supported by an in-house haemato-pathologist and a residency and fellowship programme for high-quality diagnosis.

Well-established palliative care unit

- The palliative care unit, which is a part of INCan, provides highly-developed services to patients, including a call centre, daily home visits and inpatient treatment within a separate unit or within a ward. Support services including pain management and psychological support are provided; in addition to patient and family education programmes and grief counselling.

Publication of treatment guidelines for haematological malignancy pathologies

- INCan develops its own treatment guidelines and protocols, which are made publically available via the internet to centres around Mexico, enabling the centre to share its wealth of knowledge on the treatment and management of haematological malignancies.

Key challenges faced in the delivery of haematological malignancy care



Coverage limitations in Seguro Popular

- Many of INCan patients are dependent on Mexico's Seguro Popular for coverage for treatments. While all treatments for children are covered by Seguro Popular, only a select number of adult haematological malignancies are covered (lymphomas and bone marrow transplants). This means adult patients with other pathologies, (e.g. leukaemias), have to fund their treatments out of pocket. As a result over 50% of patients diagnosed are unable to afford their care. Whilst BMT is covered, many of the supportive drugs required for haploidentical transplant are not, thus further restricting access to BMT; 75% of those eligible will not have a suitable allogenic donor.

Limited collaboration across multiple National Institutes

- The National Institutes of Mexico (e.g. Cancer, Paediatrics, Nutrition, Genomics) have limited means of collaboration; which if improved could provide more seamless and higher quality care for patients. It may also lead to better and more efficient use of resources.

Limitations in trained specialists

- While the team within INCan for haematological malignancies are specialised, there is a general shortage of specialist staff, particularly within the nursing team. This may be due to variations in regional training programmes which results in varying levels of quality.



A leading centre in Mexico for the provision of haematological malignancy care (cont.)

Instituto Nacional de Cancerología is a third level hospital from the network of public hospitals and services, and is the largest in Mexico. It is a specialist hospital with many referral departments, with the haematology being one of them.

Haematological malignancy specialty unit



Services:	Largest hospital for care of adult cancer patients in Mexico. Serves as a tertiary centre; with patient referrals from within Ciudad de Mexico and wider regions.	Collaborations:	Multiple collaborations with local (e.g. University of Mexico) and international organisations.
Resources:	Treatment of all haematological malignancies with in (radio-surgery) and out-patient treatment, diagnostic and prognostic (PET) services, BMT unit and palliative care.	Funding:	Primarily government funded, with ~\$100m (USD) a year received for construction of new premises. Certified to provide multiple treatments covered under Seguro Popular. Other funding sources include foundations (e.g. Hereditary Cancer Unit), NGOs and industry-funded clinical trials.
Teaching:	Internal training for specialists (250 training courses), nurses (quality of care, critical care, radiotherapy etc.) and haematopathology.	Haematologist(s):	17- 18 haematology fellows.

The patients



Geographic scope:	Primarily Ciudad de Mexico; however patients may be transferred from the wider region.
Patient population:	Adult referral patients only, from either public or private setting (complete diagnosis or high level of suspicion of cancer required).
Number of patients:	~100 patients/day for diagnosis, ~10-15 new HM patients per day, ~50 of all cancer surgeries, ~150 endoscopies.
Patients' characteristics:	Diagnosed already or with a high level of suspicion of cancer/benign haematology diseases.



There are a very high number of specialised initiatives for patient support

Haematological malignancies patient journey

Non-journey-specific



Haematological malignancy awareness programme

- Video (narrated by Dr. Menses) to raise awareness of leukaemia among the general population.

Diagnosis awareness programme for physicians

- Planning to develop a training programme for physicians to better detect haematological malignancy pathologies.

High-risk cancer screening programme

- Hereditary cancer clinic for tracking high risk individuals.

Comprehensive diagnostic suite

- Specialised team and technology means patients diagnosed and treatment initiated within same day or 48 hours.

Fast-track referral programme

- Abbreviated referral route for advanced/acute patients; admin is carried out in referring centre.

Haemato-pathologist training

- Training programme for pathologists from across South America.

Specialised clinics for each haematological malignancy indication

- Patients are managed within specialised groups per indication.

Psycho-oncologist support

- Specialist psycho-oncologist in haematological malignancies is available to support patients through their time as inpatients.

24/7 outpatient clinic

- A round the clock outpatient unit is available for patients; maximising efficiency and time to treatment.

Access to novel medicines

- Use of clinical trials and compassionate use programmes to access novel treatments.

Navigators

- Specialist team dedicated to supporting patients navigate hospital (e.g. tests) throughout their care.



Blue text = Case study available



Phase 3b
Bone marrow transplantation



Phase 3c
Monitoring and follow-up



Phase 4
Palliative care

Pre-transplant navigation

- Regular education seminars for patients and families; step by step guides of all required pre-BMT tests.

Multidisciplinary evaluation

- Patients undergo evaluation by extended haematological malignancy care team; supported by dedicated navigators.

Bone marrow transplant awareness programme

- A programme of education and sharing of guidelines to educate physicians in assessing eligibility for BMT.

Flexible follow-up protocols

- Follow-up for MRD is conducted either monthly, quarterly or bi-annually as determined by the attending physician.

Dedicated palliative care unit and team

- Well-established team providing integrated care with the haematology department to patients at home and in hospital.

Patient and family empowerment to manage palliative care

- Detailed education, information and support services provided to enable patient and family to direct and manage palliative care.

Clinical research focus

- Dedicated clinical research infrastructure, and there is a requirement for all staff to contribute to the centre's output.

Patient feedback

- Feedback from patients and their families is actively collected throughout the facility.

Guideline adaptation and publication

- Working alongside government bodies to develop guidelines.



The centre defined focused teams by haematological malignancy indication

Key features of the haematological malignancy care delivery team:



- Specialist teams to manage each haematological malignancy indication, (e.g. ALL or CML).
- Established diagnostic and prognostic capabilities (where patient is able to pay) delivered through a specialised team.
- Active participation in clinical trials to access latest medication, (e.g. 100% of patients being treated for CML are currently on clinical trials).
- Interdisciplinary care provided through specialised teams, (e.g. psycho-oncology, nutrition, dental care) and regular multidisciplinary team meetings to align on treatment route for haematological malignancy patients.
- Social care and on-site 'navigators' to support patients with administrative work (e.g. access to funding) and guidance through the treatment process, such as information on physical location of various laboratories/information on supportive services, (e.g. yoga).
- Social workers and 'navigators' leverage a strong network of foundations and NGO's to help support patients who are unable to receive or afford treatment and care.
- Dedicated palliative care unit, delivering care to patients both within the hospital and at home.

Governance and processes



Team meetings:

Functional units for most important units meet two times a week in delivery of care. Cases presented and critical route is created for each patient.

Patient records:

All patient records are stored on INCanet, with an EMR for all patients. All physicians and navigators have access (at different levels depending on requirements).

Pharmacy:

In-house pharmacy organised by patient need, not clinical speciality; including a specialist chemist for cytostatics, to make and dispense all drugs on-site. INCan has its own cyclotron onsite.



How can haematological malignancy care be improved?

What is next for the centre?



Improve quality of samples (both in-house and externally)

The quality of samples (e.g. biopsies) from both in-house and external hospitals can vary significantly. This is linked to limitations in training, techniques and availability of technologies, with little to no standardisation across Mexico. This often leads to delays in diagnosis, at times requiring new samples to be taken from the patient.

Evolve ambulatory services

There is currently limited resource for ambulatory services, (e.g. chemotherapy), and therefore it is only being provided in special cases. Expansion of this service and moving more patients from inpatient to outpatient treatments would be key in reducing patient burden as well as help to reduce hospital and treatment costs.

Introduce new treatments

Ability to access new, expensive drugs on the market continues to be a key issue. While currently a high number of patients are on clinical trials (e.g. 100% of CML patients are on a clinical trial), more could be done for systematic access to newest treatments on the market.

What advice would you give to less-specialised centres?



Involve state government

Fostering this relationship will help to create awareness within governmental departments of the impact and effects of haematological malignancies on the patient, and help to advocate reasoning behind changing policy and additional funding hospitals.

Seek access to public-private partnerships

If possible these partnerships (e.g. federal & local funds) will ensure the required level of funding to provide service. However, it is also important to maintain independence of the hospital from the government.



Case Studies



High-risk cancer screening programme



Overview

A dedicated hereditary cancer risk centre set-up for identification and tracking of high-risk individuals.

What is the rationale?



The strong degree of genetic linkage in many cancers, coupled with advanced profiling techniques, mean the opportunity for early detection and treatment are increasing. The hereditary cancer risk centre at INCan was set-up with the purpose of rapid identification and tracking of high-risk individuals (defined as relatives of current INCan patients with mutations predisposing to disease) to enable prevention or better treatment.

What are the key features of the initiative?



When a patient with a suspected genetic abnormality is detected during diagnosis or treatment, the family is invited to come into INCan for a free screening.

An on-site geneticist is available to assess all tests and speak with the patients.

Following testing, follow-up care (e.g. continued testing, awareness education) is offered to the family. There are very controlled protocols in place to manage the level and type of information that is provided to patients.

The unit is funded by a specialised and ring-fenced budget that is contributed to by patrons of the hospital.

What is the additional staffing requirement?



A dedicated unit with specialists (geneticists) and nurses, with a corresponding support teams.

What are the challenges faced by the initiative?



Funding for set-up of unit, this was overcome by engaging the hospital patrons to provide dedicated funding towards development and continued maintenance.

What is the impact?



Opportunity for early detection of hereditary cancers, which may enable better treatment and improved management of patients and associated costs.

What are the challenges of replicating this?



Funding for setting up the screening unit.

Specialised resources, such as geneticists.

Protocols for detection of index cases, such as patient information management.



Psycho-oncologist support



Overview

A specialised team of psycho-oncologists are available to provide interdisciplinary support to patients. There is a dedicated team for haematological malignancy patient care.

What is the rationale?



Effective management of lifestyle, social and psychological aspects of a cancer patient are as important as medical treatment to ensure the patient has very high quality of life. In order to support this, INCan has a dedicated team of 36 psycho-oncologists are specially trained within multiple cancer pathologies, (e.g. breast cancer, head and neck and haematological malignancies).

What are the key features of the initiative?



Trained specialists and residency programme dedicated to psycho-oncology. The team have dedicated one year post-qualification for specialist training in psycho-oncology.

There is dedicated support for haematological malignancy patients to address key issues:

- Dealing with rapid diagnosis (due to asymptomatic early stages of the diseases)
- Lengthy treatment times and management of co-infections.
- Need for BMT, and possible consequences, such as infertility.

Acute patients are seen by psycho-oncologists on a weekly basis. For chronic patients this may be on a monthly basis or before and after key interventions.

The team also works closely with haematological malignancy doctors to ensure collaboration in patient treatment plans.

What is the additional staffing requirement?



No additional resources on top of psychologists available; may require additional training.

What are the challenges faced by the initiative?



Cost of psychological support is not covered by Seguro Popular; however as patients are paying minimal amounts for care they are often able to pay for psychological support where needed.

What is the impact?



Improved patient management through specialised teams that understand the requirements in each cancer pathology.

What are the challenges of replicating this?



Time and resourcing to provide required training for staff to become specialised psycho-oncologists.

Haematological oncology patients often need special attention because of the nature of the pathology which can be very rapid in onset.



Psycho-oncologist



24/7 outpatient clinic



Overview

The outpatient clinic is open 24h/7 days a week; enabling rapid and continuous treatment to patients with both solid and haematological malignancies.

What is the rationale?



The high volume of patients requiring chemotherapy has meant a need for high capacity facilities. To address this, INCAn designed its new out-patient clinic to function 24h, 7 days a week.

What are the key features of the initiative?



Generally in Mexico, the start of treatment post-diagnosis can be delayed for weeks or even months. However, at INCAn they are able to offer same-day treatments. This could happen one to two hours after diagnosis at best cases; with others facing a minor delay, e.g. eight hours wait post-diagnosis to initiate treatment.

The facility operates at a high capacity, with 65-80 patients per day and about 15 overnight, with ~160 per 24hrs. There is a combination of beds and chairs for the patients.

All prescriptions are electronic minimising errors in transmission of transcriptions, with infusion and volume fully detailed. There are 11 chemists for preparation; seven in the evening; one at night and two at weekends. There is a specialised chemist for the preparation of cytostatic medication.

There are eight nurses during the day; seven in the afternoon; three at night and one at weekends.

All patients are provided with central catheters rather than peripheral, which can last up to three to four years. A specialised unit exists to provide care for central catheters on site.

There is a patient education programme in place, to provide information on treatment, such as care of catheters etc.

What is the additional staffing requirement?



Significant nurse, technician and pharmacy support is needed to enable this initiative.

What are the challenges faced by the initiative?



A significant amount of funding is required for set-up of maintenance of the clinic, and this was addressed through the expansion project where the unit was a priority. Next step would be to provide more care in ambulatory settings; as this would enable more patients to be treated in convenient locations. Key issue with this is not only the resource requirements but the intensity of the treatments for haematological malignancies.

What is the impact?



24/7 operation enables patient treatment to begin rapidly post-diagnosis (may be within one to two hours since diagnosis). This also adds to patient convenience as there are more options for when they need to come in for their treatment. As a result of this, INCAn is able to offer high-quality and convenient service for patients throughout the year.

What are the challenges of replicating this?



Significant funding is required for infrastructure, maintenance and resources.



Other hospitals can see delays of weeks from diagnosis to treatment. We can offer same day treatment.



Outpatient unit nurse



Access to novel medicines



Overview

INCan has established a number of tactics to permit access to novel targeted therapies for its patients. This has been made possible by a strong relationship with industry players.

What is the rationale?



Access to novel targeted therapies is a significant challenge in Mexico and across the Latin America region. INCan has sought to overcome this challenge by forming robust relationships with industry players, allowing them to implement an extensive clinical trial programme and compassionate-use programme.

What are the key features of the initiative?



INCan is able to gain access to novel treatments and medicines that are not reimbursed through Seguro Popular via two methods, both of which are derived from the strong relationship the institute has developed with the pharmaceutical industry.

1. Clinical trial participation

INCan have one building entirely devoted to carrying out clinical research. In addition to this it is a requirement that all staff are involved in some research, whether basic or clinical research.

In haematology, ~50% of acute patients and 100% of CML patients are enrolled in trials to gain access to novel drugs (e.g. ibrutinib).

2. Compassionate-use programme

Pharmaceutical companies have lobbyists instilled at INCan to ease compassionate use initiative. This offers pharma companies the ability to generate physician experience with their therapies prior to reimbursement status approval.

What is the additional staffing requirement?



Clinical trial focused staffing requirement (e.g. data managers, trial coordinators).

What are the challenges faced by the initiative?



Both of these methods to address the lack of access to novel therapies are made possible due to the relationship INCan has established with the pharmaceutical industry players.

This relationship was established due to ongoing interaction and prominence in the national healthcare system.

What is the impact?



Patients gain access to novel targeted therapies, who otherwise would not have had the possibility to be treated with these drugs. This delivers significant patient benefit both in terms of patient burden (i.e. as many novel therapies are orally administered), and patient outcomes.

What are the challenges of replicating this?



Cost and resources required to establish eligible clinical trial infrastructure to be included in industry sponsored clinical trials .

Relationships with pharmaceutical companies, and effective internal processes to drive the use of novel treatments via the compassionate-use programme.



We need to be more imaginative in how drugs are accessed and new treatments are introduced. We run many different programmes in order to make this happen.



Haematologist



Bone marrow transplant awareness programme



Overview

A physician-focused effort to increase education around eligibility of haematological malignancy patients for bone marrow transplant (BMT), and when and how to refer their patients.

What is the rationale?



Few physicians in primary and secondary care in regional hospitals are aware of the criteria for eligibility for bone marrow transplants in haematological malignancy patients, and how to evaluate it. This stems from the fact that due to the cost and the limited number of centres accredited to perform bone marrow transplant, few physicians have direct experience of the procedure. This means that eligible patients are potentially being denied the standard of care in their disease due to a lack of understanding by local physicians.

What are the key features of the initiative?



INCan is launching a programme targeting local physicians, to educate them to know when a patient with haematological malignancy is a bone marrow transplant candidate, and when and how to refer them to a suitable centre for treatment. This information will be disseminated via:

- A webpage with defined guidelines regarding how to evaluate eligibility for bone marrow transplant, and the correct pathway and contacts required for timely referral of eligible patients.
- A fully sponsored meeting hosted every two years by INCan, with the purpose of advertising its bone marrow transplant services for both local and regional physicians. All hospitals with haematology physicians in Mexico are invited to take part in this meeting.

What is the additional staffing requirement?



Time from specialists to collate treatment guidelines, and staff to organise the logistics required to hold a meeting.

What are the challenges faced by the initiative?



Identifying the platforms and forums where this programme can be delivered to as many regional/local physicians as possible.

Defining criteria for identification of potential bone marrow transplant candidates.

Facilities for bone marrow transplant are not widely available to regional primary and secondary care physicians.

What is the impact?



INCan has expanded the number of hospitals in its referral network for bone marrow transplant services, potentially giving access to patients who would not have previously received this treatment.

What are the challenges of replicating this?



Ensuring that all staff are engaged with the project and buy into the changes.

Development of guidelines to be analysed and adhered to.

Providing a platform for standardisation of protocols and treatment referral plans.



Dedicated palliative care unit and team



Overview

Well-established palliative care unit with a call centre, in-hospital treatment and ambulatory care, providing high-quality medical and supportive care within the hospital or in the patient's home.

What is the rationale?



Comprehensive palliative care is a key requirement in ensuring high-quality patient care; particularly given the aggressive nature of certain haematological malignancies. Due to limitations in early diagnosis capabilities externally, some patients are sent directly to palliative care upon admission at INCAn.

What are the key features of the initiative?



The unit was started five years ago and comprises of a dedicated in-patient unit, a call centre and an ambulatory unit for home visits. There is a large team that is dedicated to provision of care:

- Two call centre attendants per day (residents or fellows);
- Palliative care specialist doctor and nursing team;
- Home visit team (nurse, doctor and social worker) participated in visits from 08:30-14:00 daily;
- Integrated care specialities, (e.g. psychologist, geriatric support, pain management specialists);
- Supplementary services, such as acupuncture;
- Social care.

The unit is also well supported by volunteers who donate time and funding, to support patients pay for therapies that are not covered by Seguro Popular.

During in-hospital treatment the patients are provided with continuous attention and their needs are assessed daily by physicians. The haematological malignancy doctors work closely with the palliative care team; although often the patients are not transferred to the

dedicated unit but rather cared for within the wards. There is a strong inclusion of family in care. Training the family to be involved in patient care can help in the management of symptoms such as pain and depression.

What is the additional staffing requirement?



While a substantial team is required for a dedicated unit (doctors, nurses, management teams), smaller elements of this initiative may be implemented with less resources, (e.g. home visits).

What are the challenges faced by the initiative?



Payment for the palliative care, as this is not covered by Seguro popular. This has been mitigated working closely with foundations and volunteers to raise awareness and money where necessary.

What is the impact?



High level of impact on patient and carer Quality of Life.

Patients have the opportunity to remain at home during their final days, or receive in-patient care. Families are supported to ensure good quality care of patients throughout.

What are the challenges of replicating this?



Resourcing, funds and facilities to provide multiple settings of care, (e.g. in patient/specialised unit/at home).

Specialty training required for management of terminal patients.



Patient and family empowerment to manage palliative care



Overview

The palliative care unit has in place a well-established education and support programme for both patients and carers, to enable optimal management throughout their disease and into their final days.

What is the rationale?



The end of life stage of haematological malignancies is a period in the patient journey that requires maximum support, for both the patient and the family. Both parties need to be well educated and informed about the process to ensure they feel adequately supported and so that they are able to manage patient care effectively, and heal following the patient's demise.

What are the key features of the initiative?



A comprehensive patient and family education and support programme, comprising:

- One-on-one patient and family education sessions conducted by a nurse.
- A notebook for patient/carer to record patients well-being, with scorecards for pain, nausea etc.
 - Notebook has both written sections and graphical sections in order to support patients and carers who may be illiterate.
- Counselling sessions throughout with psychologists to ensure patient and family mental well-being.
- After patients demise, a private session is held with the family, as well as the doctors and nurses who cared for the patient. This is held to ensure family have an opportunity to speak about the patient and begin the road to healing.

What is the additional staffing requirement?



Limited additional staff – dedication of time to one on one sessions may be required, in addition to creation of collateral (e.g. notebooks).

What are the challenges faced by the initiative?



Ensuring that the language and materials used to educate the patient and their families are suitable given their educational background.

Efforts were made to use layman's terms in documents, and to communicate as much as possible in pictures.

What is the impact?



The patient feels much more engaged with their disease and treatment, and feels supported by their family and staff leading to increased patient satisfaction and Quality of Life.

The families have awareness of the palliative care process and feel involved in the treatment as well as supported following their relatives demise.

What are the challenges of replicating this?



Development of materials for education sessions around end of life care.

Time and resources of nurses and physicians to deliver this care.

Availability of psychologists to provide counselling for both patients, families and physicians.



If we don't help the family, then who is going to help the patient?



Palliative care unit manager



Guideline adaptation and publication



Overview

INCan works with government bodies to develop guidelines for treatment of haematological malignancies, in the context of the Mexican healthcare system, and publishes these guidelines for use by centres throughout Mexico.

What is the rationale?



There are a number of widely published international guidelines for treatment of haematological malignancies; NCCN guidelines from the US, and ESMO guideline from the EU, along with national guidelines across many EU countries are publicly available. Mexico does not have national guidelines for the treatment of haematological malignancies, and the international guidelines available do not necessarily account for the factors the national environment and overall characteristics of the Mexican healthcare system. INCan aims to establish a consensus document for treatment of haematological malignancies, adapted appropriately to the national situation.

What are the key features of the initiative?



INCan coordinates the development of the National Programme of Control of Cancer (PNCC), which includes five central themes, one of which is the generation and publication of oncological guides for the 10 most frequent neoplasms in Mexico.

Of the 10 neoplasms, a number of those are within the haematological malignancy space, including guidelines for Chronic Myeloid Leukaemia and non-Hodgkin Lymphoma.

What is the additional staffing requirement?



An individual who is able to liaise with governmental bodies in order to adapt guidelines.

What are the challenges faced by the initiative?



Alignment and buy-in from key stakeholders in the national oncology space, both from government bodies and healthcare institutions.

Ensuring guidelines are current and applicable across the country.

What is the impact?



Establishing consensus guidelines for the treatment and management of the 10 highest burden haematological malignancies in Mexico, enables the standardised delivery of care by Mexican specialists. This will both ensure the optimisation of resource allocation and usage in addition to improving clinical and patient reported outcomes.

What are the challenges of replicating this?



Centres looking to replicate this require a reputational standing within the national haematological community which is on par with the best centres in the country.



Hospital Regional de Alta Especialidad de Ixtapaluca (HRAE)

Department of Haematology

Ixtapaluca, Mexico

—

KPMG, June 2017





Summary

A forward thinking and open culture is a key strength of the HRAEI haematological malignancy team

Key findings from the centre



Young team empowered to drive improvements to the provision of patient care

- The extended delivery team within haematology (and the wider hospital setting), are empowered by the centre management to drive improvements to the provision of care. The centre director is fully open to adapting new practices and processes, inline with improving patient benefit, actively encouraging all staff to suggest any innovative ideas or improvements wherever they see them.

Strong multidisciplinary team approach to patient care and management

- The haematology team is fully integrated within a larger multidisciplinary team. This ensures that all patients are effectively managed by the MDT throughout the entire patient journey and even following their discharge.

Focus on care of pregnancy with cancer

- Pregnancy in cancer patients is a poorly understood condition and due to the complex nature of the cases they are seen as a high-risk patient group, with highly specific needs. At HRAEI, pregnant women are afforded priority care throughout the hospital. The centre has established CREHER, a specific clinic for management of pregnant patients who have cancer, and the only one of its type in Mexico.

Strong and open communication culture

- All stakeholders across the centre, from the haematology team and extended care delivery team to the hospital management and administrative support staff, communicate using WhatsApp. Specific groups are established for individual teams, initiatives and events.

Key challenges faced in the delivery of haematological malignancy care



Limited awareness of haematological malignancies in the community

- In the community there is a low level of awareness and understanding of haematological malignancy conditions. This is true for both the patient population (i.e. their ability to recognise symptoms and seek care), and the regional physician population in both primary and secondary care (i.e. their understanding of presenting symptoms and when to refer patients). This ultimately results in a majority of diseases presenting at late and advanced stages of progression.

Coverage limitations in Seguro Popular

- Mexico's Seguro Popular, on which many of HRAEI's patients are dependent on, covers only a limited number of haematological malignancies for adults (lymphomas and bone marrow transplants). This means adult patients with other pathologies, (e.g. leukaemias), have to fund their treatments themselves.



Haematology is situated in a large, third level public hospital (cont.)

Haematological malignancy specialty unit



Services:	HRAEI is one of the five regional hospitals devoted to the provision of speciality care in Mexico. Initially established solely as a tertiary care centre, the hospital has expanded to offer some secondary care. There is a specific focus on malignancy in pregnant patients. The centre is founded around three pillars: medical attention; development and training of staff and research.	Collaborations:	HRAEI has an established collaboration with other centres for referral of complex cytology samples to a specialist haemato-pathologist for a specialist opinion. Elsevier partnership for scientific access to patient education and information. SAFE – third party provider of chemotherapy drug preparation.
Resources:	Treatment of all haematological malignancies in both the in-patient and out-patient care setting. BMT is not currently available.	Funding:	The hospital is funded through a public-private venture (PPS), with state funding used to buy-back the assets over a 25 year period. This is inclusive of both the property and machines. During this period, the private bodies are responsible for maintenance and servicing of the assets. They also work with a number of foundations to elicit funding when required.
Teaching:	n/a	Haematologist(s):	Four haematologists.

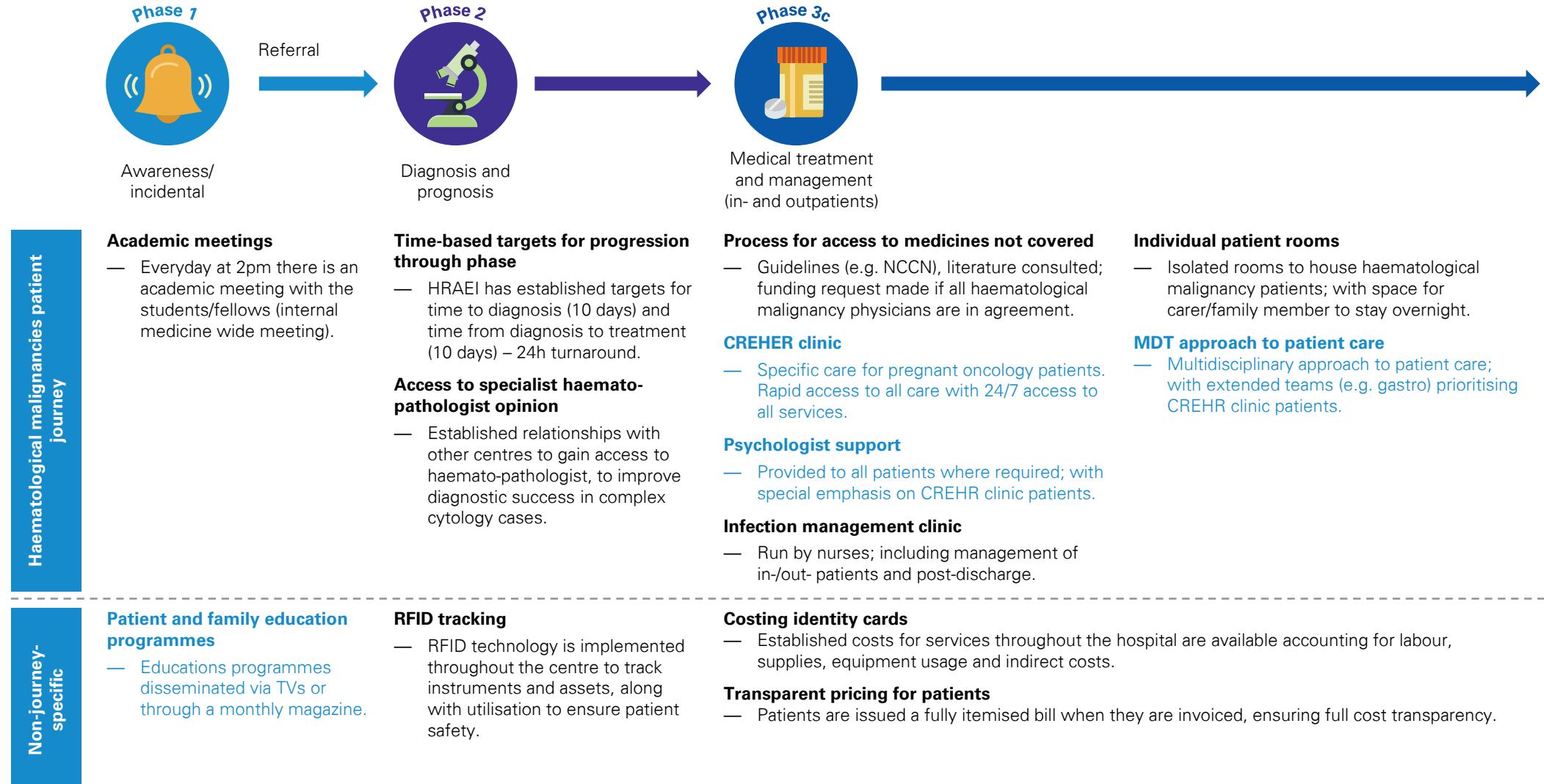
The patients



Geographic scope:	The centre covers 52 municipalities in Edo. De Mexico and 42 municipalities in Hidalgo.
Patients' characteristics:	73% patients in tertiary care; 26% patients in secondary care; 1% patients in primary care.



There are a very high number of specialised initiatives for patient support





Blue text = Case study available



Phase 3b
Bone marrow transplantation

n/a



Phase 3a
Monitoring and follow-up

Nurse-led procedure clinics

- Trained nurses manage specific clinics, including catheterisation by ultrasound and wound care.

Patient feedback

- Social workers disseminate patient surveys on a continuous basis to help generate feedback and action changes.



Phase 4
Palliative care

Community-based palliative care service

- Training provided to community physicians and telephone-based palliative services for patients who prefer to remain at home.

CISFA (pharmacy)

- Integrated pharmacy for accurate pharmacotherapy for the hospital and surrounding region.

Haematological malignancies specialised social care support

- Establishing personal relationships with haematological malignancy patients, supporting in access to social and other forms of care (e.g. housing).



The centre different MDTs that specialise in various haematological malignancy pathologies

Key features of the haematological malignancy care delivery team:



- Operates as one arm of the broader internal medicine department, ensuring a truly MDT approach to patient care.
- Five clinics defined by indication: benign haematology clinic, lymphoma clinic, plasma cell neoplasm clinic, homeostasis and thrombosis clinic and the CREHER clinic.
- CREHER clinic is a focused clinic for patients with cancer who are also pregnant, which benefits from prioritised status within the hospital. Care is coordinated between gynaecology and haematology.
- An infection prevention clinic, a wound clinic and a catheterisation clinic, are all available to both inpatients and outpatients.
- Oncology specialist nurses provide specific care and fulfil a number of additional coordination roles for patients in both the inpatient and outpatient setting, easing their journey through the system.
- Follow-up medical care and palliative care support can be provided in patients homes.
- Psychologist support to patients, in both the inpatient and outpatient setting if they request it.
- Social workers present throughout the patient journey, from the point of admission to follow-up.
- Communication is constant between all member of the care delivery team, through the use of WhatsApp across all groups in the hospital.

Governance and processes



Team meetings:

The full internal medicine MDT team is involved throughout the patient journey, with organised meetings weekly on Thursday for difficult cases.

Patient records:

All medical records and outcomes are stored in a fully integrated electronic system, accessible by all stakeholders requiring access.

Pharmacy:

Pharmacy system is fully integrated with the prescription and clinical systems established in the hospital.



For the last five years we have been working to implement integral systems focused on patient care.

Hospital Director, Haemato-oncology





How haematological malignancy care can be improved?

What is next for the centre?



Increasing BMT capabilities

Currently the service is only capable of performing children's BMT, and adult patients requiring BMT are transferred to other accredited centres (such as INCan). BMT facilities are currently being built at the centre and should be completed next year. Following this the centre will seek accreditation.

Use collected data for analysis

Currently all patient information and treatment outcomes are captured by the care team on both paper and the EMR system. However at the current time the hospital does not use any of this data for analysis.

Improve capabilities to manage lower specialties (secondary and primary care)

Currently the hospital is highly-specialised and would benefit from expanding facilities that would enable areas that are less specialised to be managed in-house. This would also require expansion of the current Emergency Department.

What advice would you give to less-specialised centres?



MDT working environment

Instilling an effective and cooperative MDT working environment is essential in developing the capabilities of your team and helps to share the decision-making process, for both in- and out-patients and consequently benefit patient outcomes.

Sharing knowledge

The sharing of findings and protocols across haematology centres in Mexico will help centres across the region to learn and maximise the reach of good practice initiatives regarding the treatment of this specific patient group. This is beneficial as there are currently no guidelines which are specific for this patient group.

Ensure effective governance processes in place

Developing a model of quality improvement is essential in progressing and encouraging good practice care within a centre. Ensuring and enabling effective governance processes to manage this will help to lead to faster and better outcomes for patients.



Give a little bit more than your need to, every day.

Chief, Haemato-oncology





Case Studies



Case study



CREHER clinic



Overview

A clinic that provides dedicated care to pregnant cancer patients, to ensure they receive safe treatment and to optimise protocols in order to prioritise the well-being of the foetus. There is a detailed process in place to guide throughout the gestation period and post-delivery.

What is the rationale?



Mexico has a high maternal mortality rate and cancer is the second most common cause of maternal death. One in 1000 pregnancies is associated with cancer, of which 25% of are haematological, 26% are breast and 26% are due to cervical-uterine cancer.

There are limited capabilities for the management of pregnant patients with cancer, often resulting in termination of the pregnancy. Therefore the clinic aims to care for the specific requirements of this high-risk population in order to reduce mortality rates of both the mothers and their babies.

What are the key features of the initiative?



Patients referred to the CREHER clinic are highly vulnerable and reliant on the hospital's support. Therefore they are provided with priority access to psychologists/psychiatrists throughout their care.

Prior to the arrival of the patient, key information regarding the patient's case is quickly disseminated to the CREHER clinic team through WhatsApp. This ensures all team member have adequate knowledge of the case prior to the patients arrival.

Upon arrival the whole MDT team attends the obstetrics unit to assess patient and decide on the actions for treatment continuation. The clinic operates a very close relationship with the gynaecology/obstetrics team. The foetus is treated as a patient in its own right and a specific treatment plan is prepared based on varying conditions.

Following discharge, all babies are followed up for five years.

Support patients through arrangement for reimbursements/funding for the treatment through the wider 'pregnancy fund' or through NGOs.

What is the additional staffing requirement?



Trained gynaecologists and oncologists, or ensuring the two departments working in close collaboration.

What are the challenges faced by the initiative?



Most of the patients referred are very vulnerable with weak emotional state due to high societal stigma of pregnancy with cancer. The clinic collaborates with psychologists/psychiatrists in order to provide emotional and mental support for the patients.

There is a lack of reimbursements via Seguro Popular for many cancer treatments associated with pregnant patients. HRAEI provides the opportunity to gain specific funding through their 'pregnancy fund' from Avon. If this does not cover the full treatment, social workers arrange additional funding through support of NGOs.

What is the impact?



The clinic has had 10 patients. There have been no miscarriages and the successful delivery of eight healthy babies.

The clinic has exceeded targets in the measurement of outcomes. Reducing the time from first meeting to diagnosis to two days (target is to achieve in <10 days) and time to diagnosis to initiate treatment to six days (the target is also <10 days).

It aims to publish its results from the treatment and management of pregnant patients, in collaboration with other centres and specialists to increase the visibility of the clinic.

What are the challenges of replicating this?



Efficient collaboration among clinical and non-clinical staff.

Access to trained specialists such as psychologist, nurses, support staff in managing pregnant oncology patients and associated stigma.

Arrangement of funds for ensuring reimbursement of required cancer treatment.



We pay equal attention to the foetus. The foetus is a patient and we care for them like a patient.





Psychological support



Overview

Psychological support offered to all haematological malignancy patients, with special emphasis on patients with pregnancy to enable them to manage both their care and that of the unborn baby.

What is the rationale?



Haematological malignancy patients, particularly those who are pregnant are highly vulnerable to psychological trauma. This may be due to often unexpected diagnosis (being symptom free) or societal pressure (e.g. stigma surrounding pregnancy during cancer treatment). HRAEI has a dedicated psychologist with a well developed programme of initiatives aimed at managing these patients.

What are the key features of the initiative?



There is a trained and dedicated psychologist who works closely with patients throughout their journey. For pregnant patients; there are a number of special protocols in place:

The patient undergoes a psychological assessment as a first step soon after arriving at the hospital. Most arrive with a high-level of stress and fear, and the psychologist works closely to help manage the emotional state. Support is also provided following the decision on continuing the pregnancy, through assessing cognitive function and ability to make decisions, emotional state and ability to face treatments while continuing with recovery, likelihood of adherence to treatment and capacity to recover (including support available from family).

CREHER clinic patients given priority; with regular sessions including family members (one to two hours at a time).

The type of support required (physical, emotional, financial) is determined and this is written into the patient care plan. Both the patient and family are given continuous education in mental health.

An environment of support is provided throughout; and all steps taken to reduce anxiety and repeated negative thinking.

What is the additional staffing requirement?



Trained psychologist(s).

What are the challenges faced by the initiative?



Managing patients who are often highly emotional with fear and anger. this is managed by working closely to address key issues, using standardised methodologies for assessment of their mental state (depression scales, behavioural cognition).

What is the impact?



Improved mental health state for both patient and family, with reduced fear and anxiety. Better preparation for both patient and family to face treatment for cancer as well as ensuring the safe arrival of the baby.

What are the challenges of replicating this?



Access to a trained psychologist.

Development or adaptation of protocols and standards to suit specific requirements of pregnant cancer patients.



We act as one big team working together with the patient and the family. There is no judgement at all, which they sometimes face from the community. We do all we can to reduce anxiety and fear and bring the patient to a more peaceful state of mind.



Psychologist



MDT approach to patient care



Overview

The complex nature of haematological malignancy conditions mean a multidisciplinary team of specialists is required for optimal patient management. This includes all new patients and those with newly diagnosed relapses.

What is the rationale?



Management of haematological malignancies requires specialist input from multiple disciplines including haemato-oncology, pathology, nurses, radiotherapy, in addition to pharmacists, palliative care, psychologists, dieticians etc. Structured MDT sessions to discuss all patients, review treatment plans and assess response is important to ensure required input is captured for optimal patient management.

What are the key features of the initiative?



A multidisciplinary team (MDT) of specialists manage all patients. This includes:

- Haematologists (each specialising in one or two haematological malignancy indications);
- General pathologist;
- Pharmacists;
- Clinical nurses;
- Psychologists;
- Additional team as required (e.g. if CREHR clinic patient, a wider team of specialists would attend – see case study).

The team meets weekly to discuss new patients; with emergency sessions held when CREHR clinic patients are admitted.

In the case of CREHR clinic patients, an PA announcement is made (together with messages through WhatsApp) to assemble the core team.

What is the additional staffing requirement?



Specialist to participate MDT meetings.

Administrative staff to coordinate the logistics of the meetings.

What are the challenges faced by the initiative?



Ensuring required specialists are available; this is currently being addressed (although primary MDT is present) additional staffing requirements remain.

What is the impact?



Optimal patient management through multi-disciplinary input into treatment plans (including decision to discontinue treatment plans).

What are the challenges of replicating this?



Availability of required specialists.

Structured programme for meetings.



It is important to give someone the right role; often team work can be very difficult because people don't get the right opportunities or there is a lot of hierarchy. It's important to find what someone is good at, and give them a chance to do that.



Chief, Haemato-oncology





Nurse-led procedures clinic



Overview

Clinics run by trained nurses for specific procedures can help to ensure patients receive care in a more timely manner, as well as free up the time of the physicians.

What is the rationale?



Haematological malignancy patients require multiple procedures throughout the treatment pathway, and this can be effectively managed by the use of trained nurses who specialise in certain techniques. By having nurse-run clinics for catheterisation by ultrasound or wound care, the hospital is able to reduce risks and improve patient management.

What are the key features of the initiative?



They have nurse-led clinics for specific procedures such as catheterisation by ultrasound or wound care. The clinics also cover follow-up of patients to ensure continuity of care, and provide patient and family education to enable self-management.

Specific training programmes have been developed in-house and are available to all nurses within the hospital.

Catheterisation by ultrasound: due to low platelet counts, some haematological malignancy patients are at a higher risk of sustaining a pneumothorax during catheterisation. Use of an ultrasound to guide the catheterisation process and reduce this risk as it requires only a single incision or puncture. When a patient is considered eligible for this, a nurse would assess and discuss with the physicians; and undertake the procedure. Currently seven nurses trained to perform this procedure.

Wound care: trained nurses manage multiple aspects of wound care, including chronic care, prevention of complications, osteomyelitis management, wet cure etc. This includes both in and out-patients. Currently two to three nurses work in the wound clinic across seven days.

CREHER clinic: they contribute to the assessment and identification of high-risk pregnant patients with the right criteria to enter the CREHER clinic program, with the approach on holistic care through all the pregnancy period, these nurses are oncology or obstetrics

specialists with some core competencies such as:

- Assessment on obstetrics risk;
- Individual orientation on oncology treatment;
- Detecting special needs on patient's and family education to take care at home;
- Follow-up in order to strengthen adherence to basic treatment, no matter what the outcome is: improvement, total cure, treatment abandonment or even death;
- Assessment of Quality of Life of these special patients.

What is the additional staffing requirement?



Trained nursing team to manage the clinic, and help develop training courses.

What are the challenges faced by the initiative?



Ensuring the required materials for training of staff.

What is the impact?



Improved patient convenience as there will be more availability of appointments.

Enhanced nurse-patient relationships, leading to better understanding of patient needs and therefore care.

Empowerment of nurses to manage key aspects of patient care.

Reduced burden on haematologists and other senior physicians.

What are the challenges of replicating this?



Training and resource requirements.



Community-based palliative care service



Overview

Palliative care provided within the home setting, for patients who prefer to remain at home. This includes training patient, family and community care physicians on delivery of care, as well as enabling remote consultations over the telephone.

What is the rationale?



The delivery of high-quality palliative care is a critical component of the patient's treatment pathway. Enabling the patient and the family to attain an optimal Quality of Life is of high importance. Often patients prefer to spend their last days at home rather than within the hospital setting, therefore this initiative seeks to enable this wherever possible/desired.

What are the key features of the initiative?



The palliative care team works closely with the haemato-oncology team to assess patient using a pre-defined set of criteria, (e.g. terminal disease, progressive or incurable disease, presence of several co-morbidities, lack of treatment options or emotional impact of therapy on the patient).

Once a patient is placed into palliative care a range of additional services are offered, such as educational materials around treatment and disease progression, and psychological and social care support for the patient and their family.

Where a patient would prefer to be at home, several options are offered:

- Telephone based consultations for symptom management (e.g. pain) by two specialist consultants (e.g. palliative care or pain specialist).
- Education and training for the family to support patient, e.g. wound care.
- Training of community care physicians to provide continuous care to the patient. In this instance, the physician is invited to HRAEI where they are provided training on wound care, pain management etc. and a schedule established.

What is the additional staffing requirement?



Dedicated palliative care specialists for phone consultations (two to four hours per day); time and resource requirements to identify local physicians (mostly through personal networks or in-house databases); and the provision of required training courses.

What are the challenges faced by the initiative?



Access to evidence-based methods for improving side effect management, (e.g. nausea or pain).

Initiating palliative care discussions at an earlier point the patient journey. This could be implemented through working more closely with the haemato-oncology team.

What is the impact?



Improve patient and family Quality of Life by being able to offer palliative care in the home setting, under the management of both a professional (e.g. trained general physician) and supportive family members.

What are the challenges of replicating this?



Trained staff with time dedicated for phone consultations.

Identification and engaging of general physicians willing to support patient in palliative care setting.



We are trying to move away from traditional way of providing palliative care and start engaging much earlier in the treatment journey and working hand in hand with the haemato-oncology team.



Palliative care specialist



Patient and family education programmes



Overview

Variety of patient education programmes, including bespoke videos, TV channels and magazines are available to inform patients and families about their treatment and management of haematological malignancies.

What is the rationale?

There is a limited awareness of haematological malignancies and their effective management within the community. As a result patients and families are often not very well informed about their condition when they arrive at the hospital. HRAEI has developed multi-channel communication strategies in order to ensure relevant and regular information is provided to patients in accessible formats.

What are the key features of the initiative?

Multi-channel communication methods that all provide patient and family education on pathologies (e.g. leukaemia), management of patients and self-care (e.g. hand washing):

- **Bespoke videos:** indication specific videos, (e.g. for leukaemia, explains treatment and possible complications). This video has been developed in-house, featuring the haematological malignancy management team, which adds to the sense of patient familiarity, comfort and trust in their care team.
- **TV channels:** TVs are fitted throughout the hospital/in-rooms featuring videos that explain topics such as: precautions and rules for friends and families; hand washing techniques; introducing the full support group responsible for care; infection management and control etc.
- **Monthly magazine:** produced by the hospital and available throughout and on the service website and intranet. The topics change monthly, covering interesting topics, ongoing initiatives and new treatment developments. This magazine is shared across five hospitals.

What is the additional staffing requirement?

A dedicated individual/team for development and dissemination of material.

What are the challenges faced by the initiative?

To ensure the language is patient friendly and accessible, overcoming issues on limitations in literacy, audible videos or graphical representations may be preferable.

What is the impact?

Patients are fully educated about their disease and the effective care required, which means physicians are able to better use their time with the patient, rather than taking on the whole responsibility of educating them. The patient instead receives some basic education from the channel.

Videos and graphical communication methods also improve patient understanding, as literacy is a key issue.

What are the challenges of replicating this?

Having access to the right types of information surrounding the disease areas and ensuring that it is patient friendly, as well as for those who are illiterate.

Having the facilities to implement educational movies in a way that is engaging and available to patients and their families individually.



Patient experience: it's not about making patients happy over quality. It's about safe care first, high-quality care and then satisfaction.



President and Founder, Association for Patient Experience

CISFA (Pharmacy)



Overview

An integrated pharmacy centre providing pharmaceutical and safety requirements in order to ensure high-quality and safe pharmacotherapy. As well as improving medicine management by taking care of the whole medication system from the selection, acquisition, storage, preparation, dispense, distribution and control to assure the correct administration.

What is the rationale?



Haematological malignancy patients require long-term, complex medication and are often suffering from co-morbidities. Therefore provision of effective medication (e.g. avoidance of polypharmacy, inadequate posology), minimisation of errors (e.g. transcriptions), and close monitoring (e.g. adverse events) is critical. Guaranteeing and ensuring adequate use of medications for patients depends on effective logistics, acquisition and management. This initiative aims to address these factors, and also minimise waste through effective management of drug inventories.

What are the key features of the initiative?



CISFA covers population from Hidalgo, Morelos, Puebla, Tlaxcala and Estado de México (coverage area of the hospital). CISFA operates 24 hour shifts and managed ~6000 prescriptions per week.

Services include (selected):

- Pharmaceutical services, such as confirmation of correct dosage, route of administration, aiding with information for both patients and health care providers. It also makes sure of rational use of drugs by the unit dosage system, internal and external medication audits, and pharmacovigilance.
- Risk management: drug monitoring and drug interactions, reporting of adverse events and pharmacovigilance. This is assessed by proactive tools in the whole medication system.



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Safety of the medication is given high consideration, with a system of triple verification of medicines in the chain of dispatch and co-responsibility of administrative control tranches. Regular audits are also performed.

Close patient relationships are maintained, with patients able to ring a number if they have questions, (e.g. do not understand dosage).

What is the additional staffing requirement?



Dedicated pharmaceutical chemists and administrative staff.

What are the challenges faced by the initiative?



Setting in place processes to ensure closer integration of the pharmacy team to the medical management team. This has now been achieved and pharmacists act as part of the MDT.

What is the impact?



Better use of resources (e.g. dispensing drugs in unit dose).

Better patient safety, improved therapy and contribution towards decreased costs due to reduction in hospital stay days.

What are the challenges of replicating this?



Funding for facilitates, such as technology, infrastructure as well as team.

Processes in place to ensure effective communication between pharmacists and other HCPs.



Haematological malignancy specialised social care support



Overview

A comprehensive support process for patients from their first arrival at the hospital until their discharge. A specialised social worker provides information and guidance of how to access the right treatment and care in a timely manner.

What is the rationale?



Patients at HRAEI are predominantly funded by the public healthcare system, and many struggle with low income. This may be compounded by low levels of education and complex living situations. Therefore the provision of adequate support is important, to ensure adherence to treatment programmes.

What are the key features of the initiative?



The social care worker is the first to interact with the patient as they arrive at the hospital. They provide information on the hospital to the patient and the orientation of their care. They also outline all documentation that would be required (this is also available online so patient is able to access from home). A socio-economic assessment is undertaken, (e.g. family structure, family networks, number of dependents, sanitary conditions such as toilets and sinks in the home).

Options for additional support is explored where required, this may be for housing that is local/better suitable for haematological malignancy patients for the duration of treatment. The hospital has a database of houses run by religious organisations or charities that can be accessed; and social workers would prepare required documentation for this, and prioritise patients based on need.

Information for management of care, (e.g. importance of follow-ups, is also shared with the patients).

What is the additional staffing requirement?



Dedicated team to manage all aspects of access to social care.

What are the challenges faced by the initiative?



Setting up the specific processes and engaging a trained team to ensure support to the patient throughout the journey. This is addressed by building personal relationships from the start.

What is the impact?



Social workers are able to develop personal relationships with the patients, understanding their unique situations and requirements. This is particularly true of the patients from the CREHER clinic, as the patients are often highly dependent on the hospital and require additional support (e.g. for the family).

What are the challenges of replicating this?



Availability and training of social care workers to deliver care. Creation of information for patients.



Hospital Ángele Lomas

Department of Haematology

Mexico City, Mexico

—

KPMG, November 2017





A multidisciplinary team provides rapid and comprehensive care to patients with haematological malignancy

Key findings from the centre



Collaboration between haematology and internal medicine

- The haematology and internal medicine teams work closely, ensuring patients receive full access to specialist care and any complications are managed in a timely manner.

Relationship with patients

- Physicians form close relationships with the patients as they remain with the patient across the treatment pathway. This relationship helps to build trust between the patient, their family and the physicians and provides a platform for sharing information on condition and treatment plans.

Access to medicines

- A number of programmes are in place to ensure rapid access to medicines, e.g. clinical trials (for both patients of Hospital Ángele Lomas and those outside, through screening programmes conducted at regional hospitals), process with COFEPRIS to access medicines not yet approved in Mexico (but have received FDA approval).

Medical Family Therapy for psychological support

- Patients and families are offered a comprehensive programme of psychological support, ensuring emotional and spiritual well-being, throughout the patient journey.

Key challenges faced in the delivery of HM care



Challenges in access to good quality care

- Private institutions such as Hospital Ángele Lomas are very expensive, and therefore limit access to general Mexican population. While universal coverage exists through Seguro Popular, this does not cover all conditions (e.g. within haematological malignancy), requiring patients to pay out of pocket which most cannot afford.

Limitations in trained specialists, e.g. nurses

- While the team within Interlomas are highly-specialised in haematology, there is a general shortage of specialist staff, particularly within the nursing team. This may be due to variations in regional training programmes which results in varying levels of quality.

Delays in diagnosis

- Patients with haematological malignancy often arrive at the hospitals in late stages, due to lack of awareness and lack of access to suitable diagnostic capabilities. These patients often suffer from multiple complications, including co-morbidities. There is a need to improve awareness and access, but also provision of integrated and palliative care for those who are diagnosed at end stages of the disease.



Interlomas is part of a large well-known private hospital group

Haematological malignancy speciality unit



Services: Interlomas is one of the 25 centres involved in the Hospital Angeles group, a private hospital group delivering care across Mexico. They have a dedicated haematology department and provide care across the treatment pathway to both adults and children.

Resources: Treatment of all haematological malignancies in both the in-patient and out-patient care setting. BMT is available.

Teaching: The hospital has links with the local university for training and teaching and shares training materials with other centres across the country.

Collaborations: — Multiple laboratories for pathology/diagnosis;
— Video education – Vida Match.

Funding: The hospital is fully funded through insurance and private individuals.

Haematologist(s): 4 haematologists.

The patients



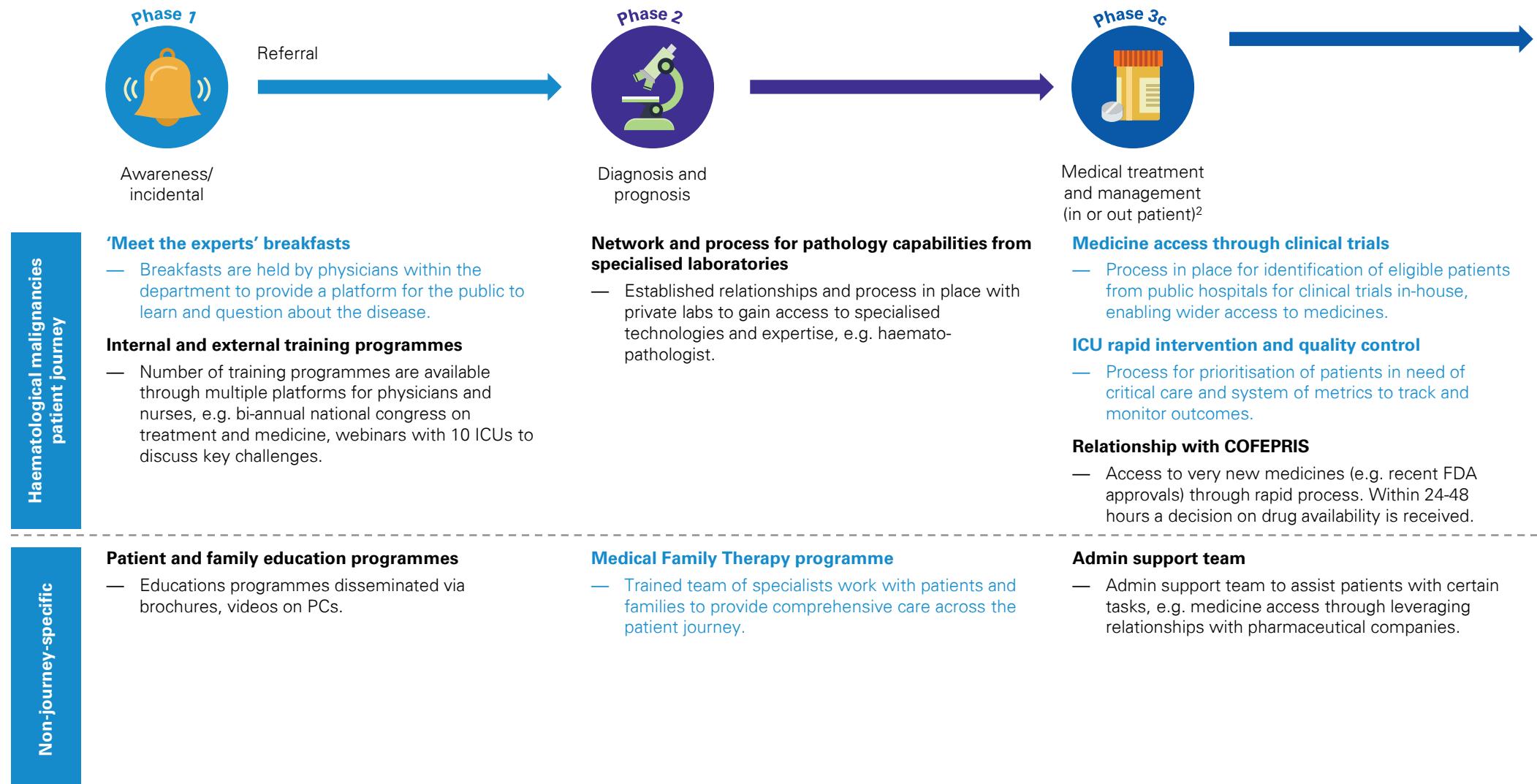
Geographic scope: The centre has a national coverage as a reference centre for haematological malignancies, receiving referred patients as well as those who have suspected diagnoses.

Patient population: Both adult and paediatric care.

Patients' characteristics: Their patient population is generally socio-economically well-off and therefore is not very diverse.



There are a very high number of specialised initiatives for patient support





Blue text = Case study available



Phase 3b
Bone marrow transplantation



Phase 3a
Monitor or follow-up¹



Phase 4
Palliative care

Contribution to registries

- Regular contributions are made to registries in an effort to track and improve outcomes, e.g. CIBMTR.

Infection control education

- Education is provided to patients (in the form of one to one sessions, brochures) to minimise risk of infections in the home environment.

Outpatient centre and day clinic

- Combined area providing outpatient chemotherapy and other services (e.g. transfusions, IV antibiotics) ensuring rapid access and patient convenience.

Community-based pain medicine

- Treatment is delivered to patients in the home who are unable to travel.

Comprehensive palliative care

- Palliative care programme (including pain management) delivered to patients at home or in the hospital. This programme is often funded out of pocket by patients.



Summary

The centre has an extensive and specialised team who implement good practice care

Key features of the HM care delivery team:



- Multidisciplinary management of patient, with regular team involving haematologist, nurse, pharmacists, infectologists, psychologists, nutritionists and internal medicine teams.
- Rapid response team from the ICU is available to help assess patients criticality and deliver intensive care to the patient wherever they are.
- Psychologists are available throughout the patient journey, for both the patient and their family. They are specialised in medical family therapy, making Hospital Ángele Lomas the only centre in the country to have this available.
- Specialised nursing team, with a bare minimum of a diploma with a specialisation in haemato-oncology.
- Psychological support is available to all of the care team, e.g. working with physicians to improve understanding of patient mental state, programmes to support physicians themselves such as Mindfulness training.
- Physicians have good communication with patients across the patient journey educating the patients about their conditions as well as helping to build trust between them.
- Follow-up care with patients in the community can be provided by the pain medicine team.

Governance and processes



Team meetings:

MDT meetings every week although physicians are encouraged to meet whenever necessary.

Patient records:

Patient records are stored electronically within the Hospital Ángele Lomas.

Pharmacy:

On-site pharmacy.



How haematological malignancy care can be improved

What's next for the centre?



Increasing in-house diagnostic capabilities

Having increased technologies (e.g. flow cytometry & immunohistochemistry) in-house will help to improve diagnostic capabilities by reducing wait times from over a week to a couple of days, enabling faster access to care for HM patients.

Greater use of data analytics

Teams within Hospital Ángeles Lomas (e.g. ICU) have large data sets that have been collected and quality controlled. The teams are now planning close analysis of this data for identification of key areas for improving performance and publication in peer-reviewed sources.

What advice would you give to less-specialised centres?



Build networks for expertise Ensure networks of experts and capabilities are available to provide services that are not available in house, e.g. diagnostics, as this will allow even smaller centres to provide a higher quality of care to patients.

Ensure greater access to medicines through seeking clinical trials Participation in clinical trials ensures access to latest medicines and treatment paradigms, and provides means of treating patients who may otherwise be unable to afford a similar quality of care. If capabilities for running clinical trials are not available in house, then centres should actively seek relationships with specialised institutions and ensure eligible patients are considered for participation.

Create an environment for collaboration Provide the haematological malignancy team with required support to collaborate widely across the hospital, e.g. ICU, ER, which will enable provision of more integrated and holistic care of patients.



Case Studies



'Meet the experts' breakfasts



Overview

Monthly meetings where an opportunity is provided to the public to hear discussion on a specific topic and meet physicians and nurses for informal discussions.

What is the rationale?



There is a need to improve awareness of medical conditions, including haematological malignancy, within the general population, however there are limited channels available for this. The 'Meet the Experts' breakfast meetings were established to address this, and provide an informal setting for the education and discussion of disease, which will help to raise awareness of the disease itself and the treatment required.

What are the key features of the initiative?



Monthly breakfasts are held at the hospital, covering a variety of disease areas including haematological malignancies. These are open to the public and free to attend.

The breakfasts are advertised in the Interlomas newsletter or by email depending on the speciality of the doctors. These breakfasts are open to anyone within the public, however the audience is often predominantly past and current patients and their families.

The session usually lasts around two hours and begins with a presentation by the physicians on a topic which if focussed on a specific need or recent development in the disease area. This is then followed by an open discussion, where the audience can question the physicians and nurses holding the session. Sometimes the sessions are supported by educational materials and brochures.

Feedback on the session is collected and collated and used to adapt following breakfast sessions. It is fully funded fully by the hospital and is free to participate.

What is the additional staffing requirement?



Time from physician and nursing team; funding for logistics (e.g. venue/breakfast).

What are the challenges faced by the initiative?



Raising awareness of these events within the wider community, further afield than those who do not receive the newsletters.

Ensuring the presentation topics are of interest.

What is the impact?



- Greater education of haematological malignancy within the public.
- Greater awareness within the hospital of patients, families and community concerns around the disease area.
- Patients and family can better manage their treatment and disease as they are well-educated around the topic.

What are the challenges of replicating this?



- Funding for logistics.
- Availability of staff and ensuring an interested community.

Until now, we have had great community interest in these sessions.



Director, Hospital Ángeles Lomas



Intensive Care Unit (ICU) rapid interventions and quality control



Overview

The ICU team have established a number of protocols for early identification and management of critical patients. There are a number of metrics regularly tracked and monitored to measure performance and the quality of care provided to patients.

What is the rationale?



Patients with haematological malignancies, particularly those who have undergone bone marrow transplants, may require intensive care support. Often these patients are admitted to the ICU at critical and late stages, and processes that enable rapid identification and response to critically ill patients can improve outcomes. A high level of quality control can be maintained through regular monitoring of agreed metrics.

What are the key features of the initiative?



Haematological malignancy patients often suffer from critical conditions, e.g. respiratory failure, sepsis, which require rapid interventions often within the ICU. The ICU team at Hospital Ángeles Lomas have in place a number of established processes to rapid identification and monitoring of patient outcomes:

- Rapid response codes: the ICU team has worked closely with physicians and nurses to establish a system of codes that identify critical patients. This enables the ICU doctors/nurses to prioritise patients, and treatment can be provided in wards if patients are too sick to be transported to the ICU.
- Use of performance metrics: the team have developed a number of metrics for assessing performance, using various guidelines (e.g. ICU index from the Society of Critical Care Medicine) including European haemodynamic guidelines for the haematopathology patients. This has enabled the team to assess their practice against other countries, national metrics and to measure performance against standards. Data is also shared with 4 other hospitals in Mexico City, and this database is currently under analysis for publication.

What is the additional staffing requirement?



ICU team and data manager (may be residents).

What are the challenges faced by the initiative?



Sufficient capacity (e.g. team members, allocated or protected time) of ICU members. Communication and training to ensure physicians use the relevant codes at the correct times.

Agreeing outcomes and ensuring correct mind-set for regular collection and documentation of data.

What is the impact?



- Reduced burden on ICU if patients are identified earlier.
- Improved patient outcomes.
- Ability to measure performance against standards and implement improvements.

What are the challenges of replicating this?



- Personnel (e.g. specialist ICU doctors and nurses).
- Infrastructure (e.g. data management systems).



We are very proud of the quality of care we provide. We have very low mortality rates within the ICU.



ICU specialist



Medicine access through clinical trials



Overview

Process for identification and enrolment of eligible patients from the wider population in clinical trials ensures wider access to those otherwise unable to afford new medical treatments, as well as ensure required patient numbers for data collection and analysis.

What is the rationale?



Access to medicines is a significant challenge in Mexico, predominantly driven by variations in healthcare coverage across the population. While clinical trials are often an effective way of ensuring patients are able to receive novel treatments, the requirements for resources, processes, infrastructure means it is not an option for many centres. Hospital Ángele Lomas physicians run programmes that identify eligible patients from public hospitals around Mexico for haematological malignancy trials.

What are the key features of the initiative?



There are a number of features that enable Hospital Ángele Lomas to effectively source the patient population and undertake clinical trials:

- **Screening programmes in public hospitals:** the Hospital Ángele Lomas haematological malignancy physicians invest time in visiting public hospitals, presenting open clinical trial protocols and ensuring local physicians are able to identify potential patients for referral.
- **Awareness campaigns:** the hospital runs multi-channel awareness campaigns to raise the profile of open clinical trials, ensuring patients are up to date. This may include advertisement via websites, newsletters, networks and social media (e.g. Facebook).
- **Protected time for clinical investigation:** members of the haematological malignancy team are able to dedicate time towards setting up and running trials, e.g. nurse and physician have 2-4 hours per day protected for running investigations.

What is the additional staffing requirement?



Dedicated and trained team members.

What are the challenges faced by the initiative?



Ensuring sufficient training and support is provided to local physicians to ensure rapid and accurate patient identification.

What is the impact?



- Wider patient access to novel medicines.
- Access to required patient population for sponsor hospital/clinical trial centre.

What are the challenges of replicating this?



- Personnel (e.g. clinical trial coordinators, data managers).
- Infrastructure (e.g. data management systems).



This gives us the opportunity to make sure as many patients as possible have access to drugs that are not available in Mexico yet.



Haemato-oncology nurse





Community-based pain medicine



Overview

Pain medicine specialists and nurses visit patients within their homes in order to deliver effective pain management. This includes all elements of treatment across the patient pathway from diagnosis to palliative care.

What is the rationale?



Patients often have limited mobility during their treatment, this may be due to a number of reasons from symptoms, prevention of infection and comorbid factors. Additionally they often have to travel long distances to receive adequate care at Hospital Ángeles Lomas.

Being able to deliver adequate care within the home, means that patients can remain in their environment and not have to travel long distances to receive this type of care.

What are the key features of the initiative?



Patients have to be classified as immobile to receive this care, this is most often within the palliative care stage of treatment.

Pain specialists and nurses deliver pain medicine care from nutrition, comfort to IV and SC drugs. The first visit is long, as the team want to get to know the patient and their disease, what treatment they are on and their symptoms. They are then usually visited once a week. However if symptoms are more severe they are seen more frequently. This is considered on a patient-by-patient basis.

If other co-morbidities are present, then additional specialists from the care team may join pain management team on the home visits.

Depending on patient preference, the pain specialists will teach the family to be involved in their care, how to deliver IV/SC. They make a clear schedule with how/when to administer the drugs. The pain medicine specialists stay close to the family so that if there are any queries or doubts they can contact the unit as and when is needed. The patients and their families are given a private number to call pain specialist in case of an emergency.

A specialist is then sent to the home and the patient is assessed. If severe they are brought in to the hospital for care.

What is the additional staffing requirement?



Specialist in pain management, supportive nursing team, resources for home visits (e.g. transport, time away from hospital).

What are the challenges faced by the initiative?



Affordability is a concern, as often pain or palliative care is not covered under insurance plans, requiring patients to pay out of pocket. Patients with complex conditions or co-morbidities may require additional support, e.g. other specialists or more frequent visits and support.

What is the impact?



- Patients can remain in the home for supportive or palliative care, rather than travelling long distances.
- Patient satisfaction is higher as they feel cared for in the home by their families.

What are the challenges of replicating this?



- Having adequate number of physicians to leave the hospital and deliver care.
- Have the transport resources.



You are here to be a support for the patients. So you have to listen to them.



Pain medicine specialist



Medical Family Therapy



Overview

Hospital Ángele Lomas offers a specialised programme of Medical Family Therapy that aims to provide comprehensive, integrated, professional support to patients and their families.

What is the rationale?



Support to ensure mental well-being of patients is critical in improving motivation, compliance and ultimately treatment outcomes. Diagnosis of a condition such as haematological malignancy may result in denial, anger or other emotional states which need careful management. Earlier intervention and close collaboration with patients and physicians is important to ensure adequate care is provided.

What are the key features of the initiative?



Psychologist team work directly with patients (do not need physicians to request input) but also as part of an MDT to ensure comprehensive patient care.

An in-depth understanding of the patient and the family is developed, including genealogy, patient belief systems, socio-economic background etc. The team act as a bridge between the patient/family and physician, and are usually present in the interim period when they are waiting to see a physician. A key element is ensuring patients understand how to speak with the physicians, what questions to ask etc., improving their autonomy.

The team play a number of key roles:

- Work directly with patients, e.g. when a patient is admitted (e.g. via ambulance to ER) who has undergone a traumatic experience or may be in need of psychological support, the team is contacted to attend to the patient directly.
- MDT participation: the team discusses haematological malignancy patients on a daily basis, and ensure physician team are up to date on any relevant information, e.g. family situation.

What is the additional staffing requirement?



Team trained in delivery of Medical Family Therapy.

What are the challenges faced by the initiative?



Patient and family may be reluctant to participate, for multiple reasons, e.g. denial of condition. They may also be very angry and aggressive, and therefore providing support at the right time is essential to ensuring adherence to treatment and care.

What is the impact?



- Better outcomes for the patients as they receive mental and emotional support across the care continuum.
- Families feel supported in assisting the care of the family members treatment.

What are the challenges of replicating this?



- Training for physicians.



We need to understand the medical situation of the patient in order to deliver the right care for them and their family.



Head of Medical Family Therapy





Hospital Maciel

Department of Haematology

Montevideo, Uruguay

KPMG, June 2017





The haematology department is situated in a large, third-level public hospital

Key findings from the centre



Split clinics by key haematological malignancy indications

- Five general clinics are available and are held by the five senior haematologists. These are split by indication: MM, CML, CLL, Lymphomas, APL. This allows for quality management, specialisation of staff, better protocol knowledge and adherence. They have three specific transplantation clinics: two focussed on post-transplant controls and follow-up services, the third one is focussed on the first contact with the programme, the bone marrow transplantation (BMT) service (considering diagnosis, criteria for transplantation, opportunity for transplantation), and with the centre.

Onsite diagnostic and prognostic laboratories working in close proximity

- In instances of acute disease, where the patient has limited time, time-to-diagnosis and consequently time-to-treatment need to be minimised to ensure the best outcome for the patient. The collaborative environment and physical proximity of the diagnostic and prognostic laboratories means that results can be obtained within 24 hours. Results of blood investigations can be accessed the same day. This all ensures that patients can be inspected in clinic in the context of a full work-up.

Comprehensive bone marrow donor programme

- Hospital Maciel offers autologous BMT, in addition to allogenic BMT, using both related and unrelated bone marrow material (obtained through the international bone marrow registry). Additionally, the centre has begun a haploidentical BMT programme, providing access to BMTs for those who would otherwise not be able to, due to the lack of a suitable donor. Additionally this reduces reliance on unrelated bone marrow banks which are expensive and are associated with significant time delay in obtaining transplant material.

Key challenges faced in the delivery of haematological malignancy care



Limitations in funding

- There are funding restrictions across the patient journey; however this is particularly an issue for those with worse prognosis (e.g. d17p in CLL) as they do not have access to systemic required treatments. Further engagement with healthcare policy makers to ensure reimbursement, and access through clinical trials is required.

Delays in diagnosis

- Diagnosis of lymphoma currently takes around two months, and is predominantly made in secondary care; reference centres are receiving patients late in their disease. Patients will relapse eventually but do not have the knowledge to identify symptoms.

National-level programmes on quality

- The quality of the medical care provided can vary significantly between public funded hospitals. Top-down programmes to improve quality systematically is required.



The haematology department is situated in a large, third-level public hospital (cont.)

Haematological malignancy specialty unit



Services:	Public hospital setting with access to all hospital departments as necessary (e.g. cardiology, neurology, intensive care etc.). In- and out-patient care of adult patients (from 15 years old) with advanced or relapsed haematological malignancies. Specialised bone marrow transplant (BMT) unit.	Collaborations:	— Porsaleu foundation (sponsored patient residence). — Institut Pasteur (translational research centre).
Resources:	Two buildings connected by link-bridge. haematological malignancy facilities include medical unit, Intensive Care Unit (ICU), BMT unit, diagnostic laboratories, central laboratories.	Funding:	Hospital Maciel is a publicly funded hospital, through the ASSE (Administration of National Public Health Care Services) system.
Teaching	Teaching hospital offering multiple resident positions in haematology.	Haematologist(s):	Five haematologists coordinators and five haematologists. Three resident haematologist.

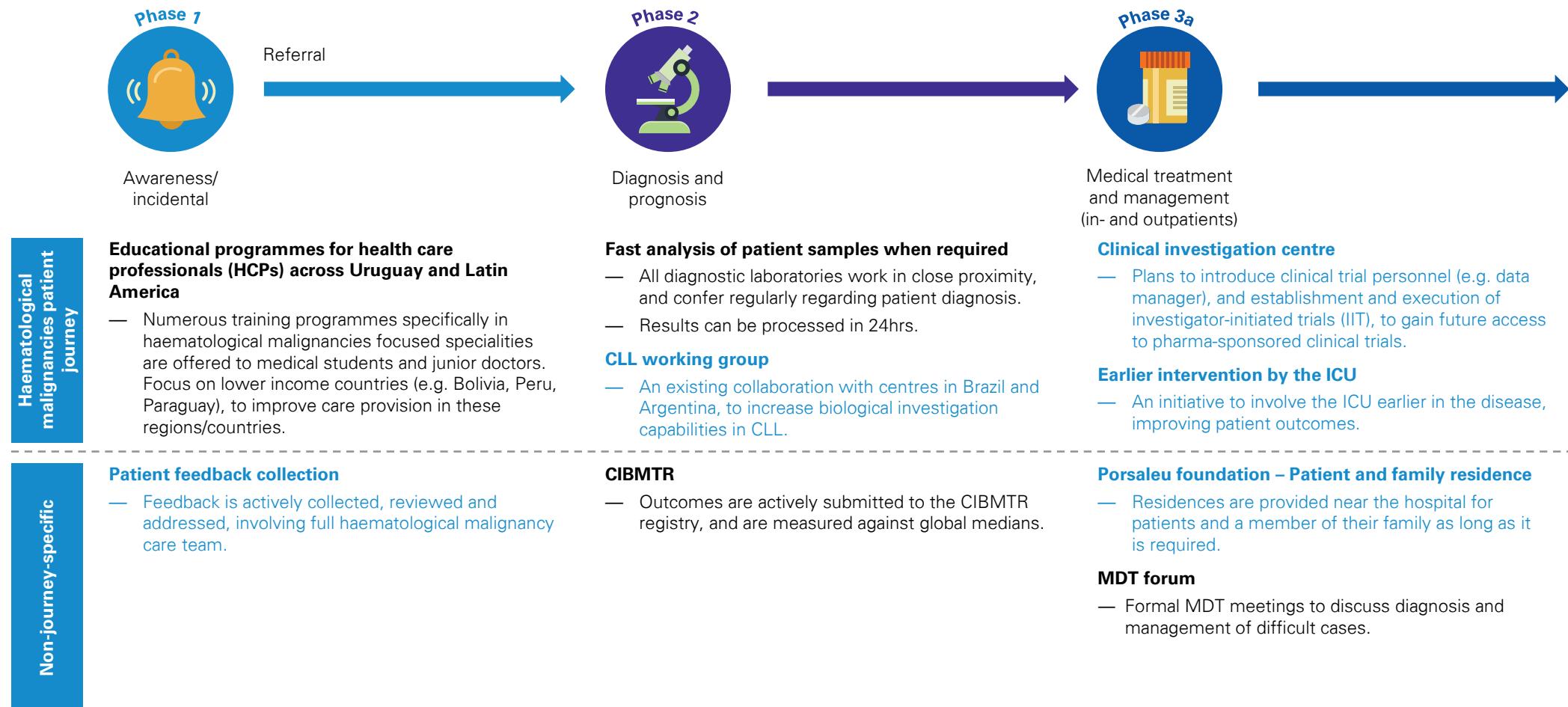
The patients



Geographic scope:	The centre has national coverage as a reference centre for haematological malignancies, receiving referred patients and those diagnosed within the general hospital.
Patient population:	Adult patients from across Uruguay. Public patients are 50% rural/50% Montevideo. Public patients are received from across the country. Patients referred to transplant are 50% from Private Care System and 50% from Public.
Number of patients:	~30 new patients taken into the service per year for Stem Cell Transplantation. 10-15 patients treated as inpatients per month. 45-50 patients treated as outpatients per week. 120-150 active patients. 1,050 chemotherapy sessions performed per year.
Patients' characteristics:	The patient population in Uruguay is genetically more similar to European/Caucasian ancestry, as oppose to the indigenous population.



There are a very high number of specialised initiatives for patient support





Blue text = Case study available



Bone marrow transplantation

Comprehensive BMT programme

- Autologous, related and unrelated allogenic and haploidentical BMT are all available.
- The prioritised order for allogenic transplant is:
 1. Direct family member;
 2. Unrelated donor through international registry;
 3. Mismatch (haploidentical) intra-familiar donors.



Monitoring and follow-up

Involvement of patients/families

- Formal meetings are held with patients to ensure they are fully informed about all aspects of their treatment and follow-up.



Palliative care

Palliative care specialist team on site

- A collaborative relationship between the palliative care and the haematology team, allowing patients to retain their haematology nurse and doctor, throughout the palliative care process.
- The palliative care team includes the pain management function.

Haematomobile - home visit service

- Home visits for mobility-restricted patients are provided.

Quality programme

- A quality control programme is being implemented to optimise time and resource usage.

Latin American training

- An active exchange programme with regional centres is in place.
- Monthly communication with Matern Infantil Hospital of La Paz, Bolivia to help improve their BMT service.



Summary

The centre different MDTs that specialise in various haematological malignancy pathologies

Key features of the haematological malignancy care delivery team:



- Multidisciplinary management of patients with regular team, involving haematologists, nurses, pharmacists, infectologists, psychologists.
- Highly collaborative diagnostics team working in close proximity (e.g. cytogenetics, flow cytometry, cytomorphology etc.).
- Intensive care team and palliative care team join the haematology team when required in a patient's journey, ensuring continuity of care.
- All of the haematological malignancy delivery team are involved in receiving feedback from patients and determining appropriate responses in order to improve the patient experience.
- There are four medical coordinators each assigned to a specific unit (i.e. inpatient unit, outpatient unit, inter-consultation and bone marrow transplant unit), handling all logistics and admin associated with normal function.
- The microbiology and virology unit is joined to the outpatient centre, in order to provide rapid testing of samples, reducing the burden on the patient as well as the outpatient unit.

Governance and processes



Team meetings:

Daily MDT meeting to discuss ongoing cases and specific 'difficult case' MDT meeting with scientific staff. Weekly SCT programme staff management meeting.

Patient records:

Patient records are currently in paper format and electronic format.

Pharmacy:

Traceability of medication is critical and ensures minimal wastage.



How can haematological malignancy care be improved?

What is next for the centre?



Greater outpatient facilities

The current outpatient clinic is too small for demand (six seats and one bed), limiting the number of patients who can be treated/seen per day. There are plans to expand the outpatient clinic.

Improved diagnostic facilities in house

Currently Hospital Maciel relies on an external provider for molecular biology studies supporting diagnostic/prognostic workup. There are plans to build a molecular biology facility in-house to improve capabilities and reduce time-to-diagnosis.

Quality improvement model (and FACT-JACIE accreditation)

Quality model is being developed in line with the National Institution for Quality (targeting Gold accreditation this year).

Expansion of the home-visit and treatment services

This activity reduces patient burden, the burden on the outpatient clinic, and saves on hospital expenditure from transportation.

What advice would you give to less-specialised centres?



Governance and processes

Centres should take a step back from their day-to-day operations to critically assess their established governance processes, and work to develop a quality model that works in their own context. Additionally centre representatives can engage with quality institutions/agencies in order to ensure the quality of their care is effectively assessed. This will expose them to quality initiatives across a wide range of sectors (not just healthcare), allowing them to benefit from cross-sector learnings as they develop their own quality models.

MDT diagnosis infrastructure

It is essential that good lines of communication exist between physicians and members of the diagnostics team (e.g. cytogenetics, cytomorphology, flow cytometry). This ensures that physicians understand the requirements for these processes, reducing time to diagnosis (e.g. through poor sample extraction and storage), and are able to better direct diagnostic and prognostic workup.



Case Studies



CLL working group



Overview

Aim to develop a better understanding, and increase the biological investigation capabilities, for chronic lymphocytic leukaemia (CLL) through establishment of a working group across Uruguay, Argentina and Brazil.

What is the rationale?



Initially the working group was established with the goal of improving the clinical management of patients across the region by developing and profiling a range of useful prognostic indicators for patients with chronic lymphocytic leukaemia. Primarily the indicators being investigated are those present in patients with 17p deletion, and those related with mutation of p53.

What are the key features of the initiative?



Participants in the group are from a number of centres across Uruguay, Argentina and Brazil, all with the collective goal of developing the biological capabilities and protocols within the region for patients with CLL.

The group meets regularly to formulate strategies for developing this initiative. To date there have been three meetings, with the third scheduled in Buenos Aires in August 2018.

This working group is pharmaceutical industry sponsored.

What is the additional staffing requirement?



No additional resource requirement; good relationships with leading haematologists in key centres in the region.

What are the challenges faced by the initiative?



To integrate more countries in this cooperative Latin American cooperative group
To generate a platform of interphase clinical biology that integrates specialists and experts from both profiles that reflects a real translational research.

What is the impact?



The establishment of this working group serves to deliver three key factors benefiting patients with chronic lymphocytic leukaemia:

1. Improved communication and collaboration between regions with regard to the care and management of haematological malignancy.
2. A better understanding of the biological factors determining a CLL patient's prognosis and treatment.
3. A forum for collaboration to establish Investigator initiated trials between centres, sharing the resource and funding requirement and generating experience in the clinical trial process.

What are the challenges of replicating this?



Building the relationships between centres to support the initiative.



Clinical Investigation Centre



Overview

Aim to develop suitable clinical trial infrastructure and gain experience of clinical trials through commencement and running of investigator-initiated trials (IIT). This will enable Hospital Maciel to eventually take part in industry sponsored trials, allowing patient access to novel drugs not currently reimbursed through the Administracion de los Servicio de Salud del Estado (ASSE).

What is the rationale?



In Uruguay, novel targeted therapies are not approved across all patient segments and indications. Two methods by which access can be attained include compassionate-use and pharma-sponsored clinical trials. However centres with no trial infrastructure or experience are seen as high-risk by pharma, and so often are not eligible to join trials. By building experience and infrastructure slowly, inclusion into clinical pharma-sponsored clinical trials can be gained.

What are the key features of the initiative?



Hospital Maciel is developing a specific unit referred to as the 'Clinical Investigation Centre'. This will involve establishing a full-time role for a data/statistical manager to handle all clinical trial related data and functions.

This will serve to position the centre as being relevant to Latin American needs and capable of conducting clinical trials in a robust accurate fashion.

The institution has an Ethics Committee who evaluates the clinical trials projects in reasonable time frames.

The department is setting up an International Multicenter Investigator-initiated trial, as a means of gaining experience with the clinical trial process.

What is the additional staffing requirement?



Data manager, statistical and clinical trial coordinator.

What are the challenges faced by the initiative?



The population of Uruguay is relatively very small compared with that of other Latin American countries (approx. 3.5 million people). Consequently coordination with other centres will be essential to ensure that adequate patient populations can be achieved to be considered for participation in clinical trials.

What is the impact?



By building experience in running clinical trials, and by establishing the infrastructure to support trials, centres will be viewed by pharma companies as viable sites for inclusion in their sponsored trials.

This will enable access of patients in these centres to novel drugs used in such trials, which are currently not reimbursed by the ASSE system, ultimately improving patient outcomes.

What are the challenges of replicating this?



Establishing the required infrastructure to satisfy industry bodies of competence in clinical trials implementation (good practice clinical research).

Identification and recruitment of dedicated and experienced personnel required for the successful running of clinical trials.



Earlier intervention by the ICU



Overview

Active intervention to increase the coordination of care between the haematology department and the Intensive Care Unit (ICU). Specifically this initiative seeks to bring the involvement of the ICU into the patient journey at an earlier stage, in an effort to improve patient outcomes.

What is the rationale?



Previously there has been a perception that when patients with haematological malignancy enter the intensive care unit, they are assumed to have a very high mortality risk (e.g. due to high septic shock risk), and that return of patients from ICU to haematology was very rare. This initiative was implemented to address this negative perception, to help ensure more patients return back to the haematology department well, which ultimately improving patient outcomes.

What are the key features of the initiative?



Patients from haematology are actively transferred to the intensive care unit earlier than would have previously occurred (i.e. before their condition is considered 'critical'). Previously patients were only transferred when they required intubation, and interventions such as BPAP were delivered in the haematology department.

There is a specific role dedicated to liaising between the haematology department and the ICU to coordinate this transfer of patients between the departments. This role is specialised in haematological malignancy.

If patients are considered terminal, they are now transferred back from ICU to the haematology department for their end-of-life care, as the environment is considered more patient friendly.

What is the additional staffing requirement?



A member of the treatment team to liaise between ICU and the haematology department to ensure earlier detection.

What are the challenges faced by the initiative?



Building the relationship between the ICU and the haematology department, to ensure physicians in both departments understand the initiative and how to ensure that care for the patient is continuous as they are transferred between the two. To achieve this, there is ongoing dialogue between the two teams, while additionally haematology residents are now required to work in the ICU for three months during their training.

What is the impact?



This initiative has an impact on both the patient and their family, as well as on the intensive care physicians. Patients and their families will see transfer to the ICU more positively in their care pathway, with a good chance of return to the haematology unit. ICU physicians will lose the mentality of associating haematology malignancy patients as being 'lost causes', and will expect to treat the patient and return them to the haematology unit. Indirectly this contributes to improved patient outcomes.

What are the challenges of replicating this?



Requires access to an ICU unit with capacity to accept haematology patients at an earlier stage of their disease.

Improved communication between the ICU and haematology physicians to work together in improving the patient's condition and coordinating care across two departments.



Before this initiative was established, most patients would die in the ICU. This is about removing the stigma that they will not come back.



Haemato-oncologist



Patient feedback collection



Overview

Active effort in place to ensure that all patients passing through the haematological malignancy unit will be given a patient questionnaire to fill out every discharge, and for this to continue into the outpatient setting .

What is the rationale?



Patient-centric care is a high priority, and as such it is important that the views of patients are collected on a regular basis. By doing this, issues in the service from a patient perspective can be quickly identified and where applicable, resolved. Ultimately this aims to improve the patient experience delivered by the haematological malignancy care team and facilities.

What are the key features of the initiative?



All patients passing through the haematological malignancy unit will be given a patient questionnaire to fill out, twice per year as long as they are treated within the service. This is given to both patients in the inpatient unit and the outpatient unit.

The patient residence foundation (Porsaleu foundation) hosts a meeting with patients every Friday, to discuss the care they have received and how they may improve it. This meeting is open to current patients staying at the Porsaleu foundation, current patients not residing at the Porsaleu foundation and patients who have been discharged from the service.

There is a broader meeting held two-three times per year in the Porsaleu residence to discuss the outputs of the questionnaires. This meeting is attended by all members of the haematological malignancy care delivery team/support staff (e.g. psychologists, social workers etc.).

Feedback from family members is also collected as a key stakeholder in care delivery.



Before this initiative was established, most patients would die in the ICU. This is about removing the stigma that they will not come back.



Haemato-oncologist

What is the additional staffing requirement?



Additional admin resources to process the feedback forms.

What are the challenges faced by the initiative?



Ensuring the questionnaire covers the correct breadth of topics in a way that is sensitive to the patients disease state.

Demonstrating that patient feedback is acted upon, and obtaining the correct funding and resources to do so.

Addressing difficult patient concerns. An example of this would be:

- Patients comment that time in hospital is too long; the department is attempting to respond to this by increasing coordination across the service to align all processes into as few visits as possible. This requires significant improvement of communication throughout the main unit and all auxiliary services, and may require the establishment of new processes and protocols.

What is the impact?



Patient care and patient experience can be improved through methods that may otherwise not be obvious to the care delivery team. An example of an action that was taken by the centre in response to feedback:

- Chairs for treatment/chemotherapy delivery were uncomfortable for long periods of time, so were changed for different models.

Patients feel more engaged with the centre and the staff.

What are the challenges of replicating this?



Agreeing frequency and format of patient feedback collection.

Assigning staff to organise and review feedback.

Obtaining resources/funding to implement changes resulting from feedback.



Porsaleu foundation – patient and family residence



Overview

Porsaleu is a foundation independent from Hospital Maciel, but effectively collaborating with them in order to provide a residence for patients and family members who are unable to afford to stay in the hospital or in a nearby hotel during the course of their treatment.

What is the rationale?



As Hospital Maciel is predominantly a reference centre for secondary care institutions (mainly from the public healthcare setting) across Uruguay, patients and their family members are often required to travel long distances, and pay large fees for accommodation nearby, in order to access the hospital's care. This initiative provides access for patients and one family member to free accommodation, and Hospital Maciel provides all of the required food for the duration of their stay, allowing them to subsequently access care otherwise beyond their means.

What are the key features of the initiative?



The residence has eight rooms, with 20 beds. These are available to any patient being treated at Haematology Maciel and/or their family (1 member) for the duration of their treatment. There is no minimum or maximum stay, and each patient is permitted one family member.

The department provides all food for the patient and one family member.

One room is always maintained empty to accommodate an emergency case which requires its use (e.g. an acute leukaemia). Emergency services are donated to the foundation as required.

This initiative is predominantly funded via charitable donations from local companies, philanthropists etc. in addition to fundraising events. There are three members of staff, a cleaner, a secretary and a social worker.

The Porsaleu foundation residence is intentionally set a couple of blocks away from the hospital, to allow the patients a sense of separation while ensuring they are close enough to easily access care.

What is the additional staffing requirement?



Social care representative, cleaning staff and administrative staff to run the facility.

What are the challenges faced by the initiative?



As all funding is through charitable donation, this is a constant challenge to the foundation. This is addressed through active fundraising events, targeting both individuals and companies.

Currently there are not enough beds for the demand. This is being addressed through the establishment of processes to assess the means of individuals requesting space in the residence (not currently performed).

What is the impact?



This initiative allows access to treatment for patients who would otherwise not be able to obtain it. Additionally it allows their family members to better support patients through their treatment by ensuring they are able to stay with the patient.

This initiative also reduces the burden on hospital facilities of admitting patients who are capable of living outside the hospital setting.

What are the challenges of replicating this?



The resources required to provide this patient/family residence. As the residence itself is provided through charitable donation, and is dependent on the availability of suitable residence near the hospital. This may not be applicable to all institutions looking to improve patient care.

Maintaining funding for an initiative such as this requires ongoing efforts by dedicated individuals.



This initiative was borne out of necessity, for people with low resources.



Porsaleu foundation representative



Haematomobile – home visit service



Overview

A service delivering care to haematological malignancy patients in the setting of their own home. These visits are conducted by one nurse and one haematologist, as part of their contracted work within the hospital, and is offered two days per week. Patients initially eligible for this service are transplant patients (immunocompromised), or those struggling with their mobility.

What is the rationale?



There are a number of instances in which patients are unable to attend the hospital to access care. This service aims to reduce the burden on these patients of making repeated visits to the hospital, and maintains the stability of their care.

What are the key features of the initiative?



A dedicated team of one haematologist and one specialist nurse are responsible for visiting patients in their homes to deliver outpatient services, the challenge is to deliver administration of chemotherapies and blood transfusion.

These HCPs are part of the established haematological malignancy care delivery team in Hospital Maciel, and as such the care provided through this service is comparable in standard to that provided through the outpatient clinic.

A key feature of this service is the ability of the HCPs to view the patient environment, and identify any aspects which may affect their disease state or treatment outcomes. They are able to make recommendations on living standards, and bring in additional support where required (e.g. psychologists).

Patients who are eligible to receive this service include those who are suffering from neutropenia (and are therefore immunocompromised), or those who have mobility issues, however cases are assessed on an individual basis and the final decision regarding who can receive this service falls to the physicians.

This service can include palliative care provision in the home if required or interact with the hospital's home care service.

What is the additional staffing requirement?



Transportation service (i.e. driver), one doctor and one nurse to carry out home visits.

What are the challenges faced by the initiative?



The initial challenge was in establishing a means by which to allow the physicians and nurses to travel to patients homes. This was circumvented through negotiation with the hospital's existing transport provision. However as these contracts are shared across all services within the hospital, there are restrictions to the service of two-day/week and provision within the main city geography. This initiative is currently established as well as in the pre-hospitalised segment as in the post-hospitalised patients.

What is the impact?



Patient satisfaction with the care provision of the hospital is improved, as they are saved the burden of making repeated visits to the hospital which may additionally fall outside of their financial capacity. This is measured informally, but plans to obtain more formalised feedback of this initiative.

Additionally this service reduces the burden on the hospitals outpatient clinic, which is capacity constrained, and the hospitals transport system (i.e. ambulance services). It also reduces contact of the immunocompromised patient with the hospital environment and saves the costs associated with these functions. The hospital does not yet collect or measure the cost savings associated with this function, but plan to in the future to support further roll out of the service.

What are the challenges of replicating this?



Gaining approval from authorities to carry out home visits.

The resources required to provide this home care (e.g. existing transport contracts or availability of contracting new services).

There must be sufficient staff to allow a home-care service without compromising the care provision within the hospital itself.



Quality programme



Overview

Aim to implement a structured programme of quality improvements across initially the BMT service, but effectively to all functions of the haemato-oncology. The goal of the programme is to ultimately improve patient outcomes and hospital resource management.

What is the rationale?



Hospital Maciel is in the process of implementing a quality improvement initiative specifically across the BMT service. However, many of the specific initiatives included in this will impact patients beyond this scope, effectively across the entire haemato-oncology patient pathway. This is being conducted in an effort to maximise patient outcomes and ensure that resources are allocated and utilised to their maximum effect. This is considered by the department as a 'self-audit', which is key to understanding where inefficiencies and wastage are impacting ability to provide care.

What are the key features of the initiative?



Hospital Maciel has an eight-point plan to improve quality across the service:

1. Collect data on, and systematically evaluate, impact of comorbidities in transplant outcomes.
2. Modify conditioning regimen in line with outcomes collated to a patient's Sorror index score.
3. Increase in number of transplants carried out from unrelated donors.
4. Produce established protocols for all procedures and treatments carried out in the unit.
5. Build a deeper relationship with the ICU, producing a structured approach to intervention and supported patient evaluation.
6. Pursue with the quality management programme and with the FACT and JACIE accreditation – a pilot programme is being launched this year, outlining a three-step process to achieving accreditation.

7. Report and measure centre outcomes against global medians as detailed in the CIBMTR registry.
8. Implement and collect data from the haplo-identical transplant programme.

What is the additional staffing requirement?



Staff to assess the measurement outcomes of the programmes.

Manager to oversee the programme as a whole.

What are the challenges faced by the initiative?



Ensuring that all staff at all levels are engaged with this process and change their ways-of-working in line with developed, standardised processes.

To do this, Hospital Maciel ensures that all staff are able to take an active part in the development and implementation of this programme, and formal meetings are held to introduce the outcomes of the programme to those staff members not involved.

What is the impact?



All procedures and processes are conducted in a standardised fashion, ensuring that results are more predictable and their conditions more manageable.

Wastage from the system through inefficient use of resources and facilities is reduced, benefiting the hospital. This will translate into improvements in patient care and management, (e.g. more patients transplanted).

What are the challenges of replicating this?



Ensuring that all staff are engaged with the project and buy into the changes.

Providing a platform for standardisation of protocols.



We need to improve not only our results but also our management.



Haemato-oncologist

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