



International Experience Exchange
with Patient Organisations

IEEPO 2020 Poster eBook

Patient Community
Experience Exchange



**FROM CHANCE
TO CHOICE:**
Creating the future
of healthcare together

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IEEPO POSTER EBOOK

> Welcome

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> Webisodes

Discover more about the poster categories by listening to our webisode series, where Bastian Hauck deep dives into these areas with experts from the Patient Community

THE POSTERS

> The Power of Data

> Digitalisation of Healthcare

> Engaging in Healthcare Transformation

> By Country

> By Therapeutic / Disease Areas

> Thanks to all organisations that submitted a poster

Welcome

Thank you for downloading the IEEPO 2020 Experience Exchange Poster eBook. This eBook reflects the collective effort of representatives from more than 40 patient organisations worldwide who initially prepared these project posters for a best practice exhibition for Berlin during IEEPO 2020.

During the months that followed many of you asked us to find another way of sharing these best practices despite our inability to meet in person. This eBook is the result. We hope it will inspire discussion and debate as well as acting as a valuable resource for you and your team.

Please join us in thanking everyone who devoted time and energy to creating and submitting an experience exchange poster for inclusion. It has been an honour to work together on making this available to the community. We would also like to extend our gratitude to the IEEPO Advisory Committees and Global PHC Patient Council for their support and expert comments throughout the submission process.



READY TO BEGIN?

To assist you in finding relevant projects quickly and easily, the posters have been organised in three theme categories:

- The Power of Data
- Digitalisation of Healthcare
- Engaging in Healthcare Transformation

You can also search posters by country and therapeutic and/or disease area

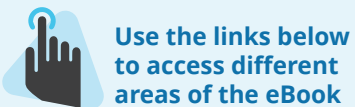
Additionally, we have included the contact details for project leads and encourage you to reach out to them with questions or comments about their projects.

We hope this will prove to be a valuable resource to the IEEPO community. Any feedback on how to make this eBook even more relevant or easy to use is encouraged.

Share your comments here.

Visit [IEEPO.COM](https://www.ieepo.com) for
even more resources
and events





Navigate this eBook based on your preferences

View the posters in these categories

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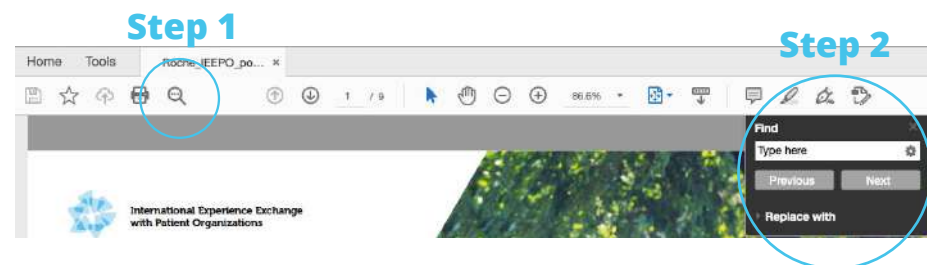
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The Power of Data

BRAZIL

ASSOCIACAO BRASILEIRA DE ESCLEROSE MULTIPLA MULTIPLE SCLEROSIS



Evaluation of the work situation of multiple sclerosis patients in relation to edss

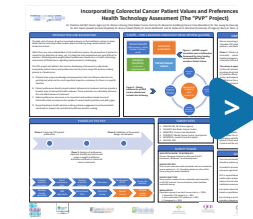
ASSOCIAÇÃO BRASIL HUNTINGTON-ABH HUNTINGTON'S DISEASE



Contributions of brazil huntingon's association (abh) to the registration of cases of huntington's disease in to the registration of cases of huntington's disease in Brazil

CANADA

COLORECTAL CANCER CANADA COLORECTAL CANCER



Incorporating Colorectal Cancer Patient Values and Preferences Into Health Technology Assessment (The "PVP" Project)

CHINA

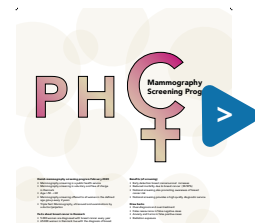
HOUSE086 LYMPHOMA



Data Initiates Real Changes in the Real World

DENMARK

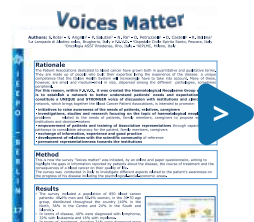
DANSH BREAST CANCER ORGANISATION DBO BREAST CANCER



PHC Mammography Screening Program

ITALY

LA LAMPADA DI ALADINO HEMATOLOGY



Voices Matter

ACTO ONLUS OVARIAN CANCER



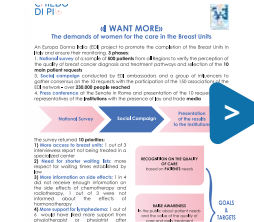
Ricerca In-Acto

FONDAZIONE LIRH HUNTINGTON'S DISEASE



Spazio Huntingdon - A Place for Children

EUROPA DONNA ITALIA BREAST CANCER



I Want More - The Demands of Women for the Care in the Breasts Units

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The Power of Data

ITALY (CONT'D)

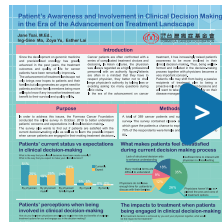
ASSOCIAZIONE NAZIONALE PERSONE CON MALATTIE REUMATOLOGICHE E RARE - APMARR APS RHEUMATOID ARTHRITIS



Living with a rheumatic disease in Italy

TAIWAN (REPUBLIC OF CHINA)

FORMOSA CANCER FOUNDATION PAN-ONCOLOGY



Patient's Awareness and Involvement in Clinical Decision Making in the Era of the Advancement on Treatment Landscapes

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PERU

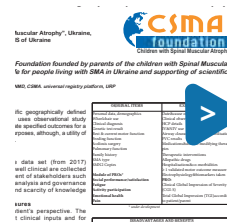
ASOCIACIÓN DE CONTRIBUYENTES DEL PERÚ NOT DISEASE AREA SPECIFIC



The Power of Data: Building patient's participation in Healthcare transformation through evidence and data

UKRAINE

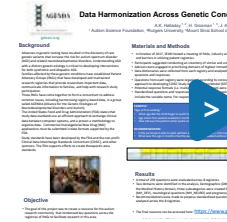
CSMA FOUNDATION SPINAL MUSCULAR ATROPHY



The specificity of collecting PROMs by "patients driven" registries for rare diseases vs "doctors driven" on example of Ukrainian Registry for Spinal Muscular Atrophy

USA

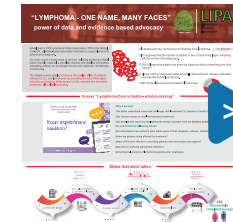
AUTISM SCIENCE FOUNDATION AUTISM SPECTRUM DISORDER



Data Harmonization Across Genetic Conditions Associated with Autism

SERBIA

LYMPHOMA PATIENT ASSOCIATION LIPA LYMPHOMA



Lymphoma - one name many faces, Power of data and evidence based advocacy



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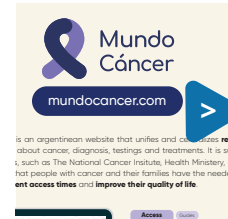
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Digitalisation of Healthcare

ARGENTINA

DONDE QUIERO ESTAR PAN-ONCOLOGY



mundocancer.com

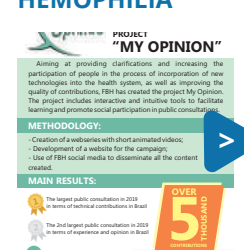
BRAZIL

FEMAMA BREAST CANCER



MAMAtch!: a journey-sharing experience - Bringing patients together through technology

FEDERACAO BRASILEIRA DE HEMOFILIA HEMOPHILIA



"My Opinion"

ITALY

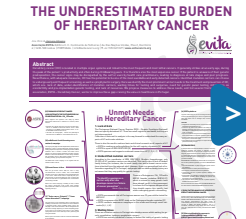
FEDEMO ONLUS (FEDERAZIONE DELLE ASSOCIAZIONI EMOFILICI ONLUS) HEMOPHILIA



Punto-e 2019 - 2020

PORTUGAL

EVITA HEREDITARY CANCER



The Underestimated Burden Of Hereditary Cancer

TAIWAN (REPUBLIC OF CHINA)

HOPE FOUNDATION FOR CANCER CARE PAN-ONCOLOGY



Using (HOPE Passport) as PHC tool to enhance cancer patient's self-management

TURKEY

SMA BENİMLE YÜRÜ SPINAL MUSCULAR ATROPHY



Patient Registry and Follow-up System for Turkish SMA Patients

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Engaging in Healthcare Transformation

AUSTRALIA

OVARIAN CANCER AUSTRALIA NOT DISEASE AREA SPECIFIC



The Australian Patient Advocacy Alliance

BRAZIL

ASSOCIACAO DOS HEMOFILICOS DO ESTADO DE SANTA CATARINA HEMOPHILIA



The 'AHESC comes to you' Project

CHINA

CHINESE ANGELMAN SYNDROME ORGANIZATION ANGELMAN SYNDROME



One For All and All For One - The Long Term Doctor-Patient Alliance for Chinese Angelman Syndrome Patients

THE ILLNESS CHALLENGE FOUNDATION PAN-RARE DISEASE



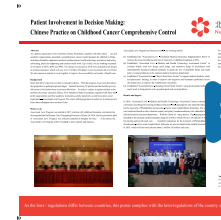
China Illness Challenge Foundation (ICF)

MDBABY CARE CENTER DUCHENNE MUSCLE DYSTROPHY



Mdbaby Care Centre, China

NEW SUNSHINE CHARITY FOUNDATION PEDIATRIC CANCER



Patient Involvement Decision Making: Chinese Practice on Childhood Cancer Comprehensive Control

ITALY

SALUTE DONNA ONLUS PAN-ONCOLOGY



Health: An Asset and a Right That Needs to be Protected and Promoted

WALCE LUNG CANCER



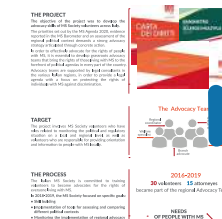
Be MUT-ual Days - Oncogene driven Cancers: The New Paradigm

FAMIGLIE SMA ONLUS SPINAL MUSCULAR ATROPHY



Progetto pilota di screening per la SMA

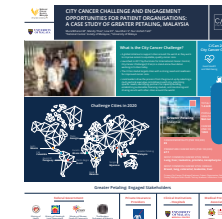
AIMS - ASSOCIAZIONE ITALIANA SCLEROSI MULTIPLA MULTIPLE SCLEROSIS



Welfare Program 2016 - 2019: Advocating for the rights of people with MS in Italy

MALAYSIA

NATIONAL CANCER SOCIETY OF MALAYSIA PAN-ONCOLOGY



City Cancer Challenge And Engagement Opportunities For Patient Organisations: A Case Study Of Greater Petaling, Malaysia

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Engaging in Healthcare Transformation

MEXICO

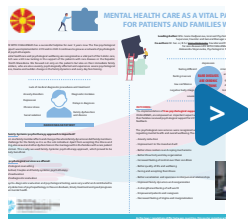
ASOCIACIÓN MEXICANA DE LUCHA CONTRA EL CÁNCER & SINTRA, ADELA AYENSA PAN-ONCOLOGY



Together Against Cancer

REPUBLIC OF NORTH MACEDONIA

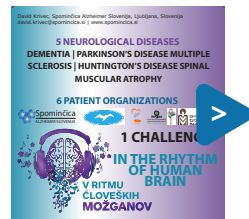
PAG LIFE WITH CHALLENGES PAN-RARE DISEASE



Mental Health Care As A Vital Part In The Holistic Care For Patients And Families With Rare Diseases

SLOVENIA

SPOMINČICA – ALZHEIMER SLOVENIA PAN-NEUROSCIENCE



In The Rhythm Of The Human Brain

SOUTH AFRICA

MULTIPLE SCLEROSIS SOUTH AFRICA MULTIPLE SCLEROSIS



Multiple Sclerosis

SWEDEN

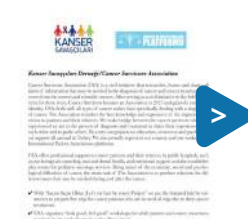
SWEDISH HEMOPHILIA SOCIETY HEMOPHILIA



To Live with Haemophilia: Quality of life study - Sweden

TURKEY

KANSER SAVAŞÇILARI PAN-ONCOLOGY



Cancer Survivors Association

PEMBE İZLER OVARIAN CANCER



Pink Route

UKRAINE

SOUL SISTERS PAN-ONCOLOGY



The Cancer Patient Forum Vol. 2 "Cancer Policy"

USA

LUNGEVITY FOUNDATION LUNG CANCER



Eliminating Disparities In Precision Medicine Through A Patient-provider Intervention

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[Contributions Of Brazil Huntington's Association \(ABH\) To The Registration Of Cases Of Huntington's Disease In To The Registration Of Cases Of Huntington's Disease In Brazil](#)
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[Lung Cancer Monitoring Platform \(Lung Cancer Radar\)](#)
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[MDbaby care center](#)
[MDbaby Care Centre, China](#)
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[New Sunshine Charity Foundation](#)
[Patient Involvement Decision Making: Chinese Practice on Childhood Cancer Comprehensive Control](#)
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DENMARK

[Dansh Breast Cancer Organisation DBO](#)
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ITALY

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[Voices Matter](#)
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[ACTO Onlus](#)
[Ricera In-Acto](#)
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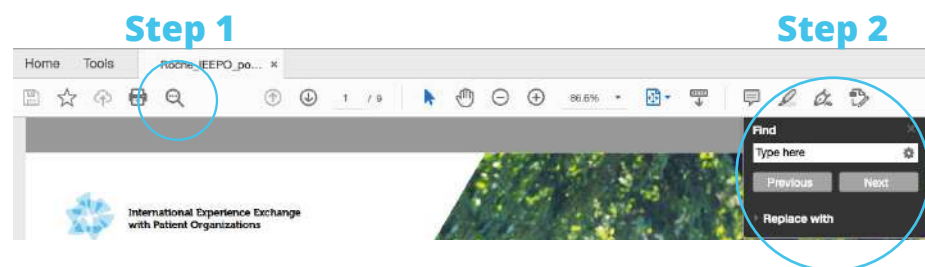
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[Spazio Huntingdon - A Place for Children](#)
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[Europa Donna Italia](#)
[I Want More - The Demands of Women for the Care in the Breasts Units](#)
The Power of Data

[Associazione Nazionale Persone con Malattie Reumatologiche e Rare - APMARR aps](#)
[Living With A Rheumatic Disease In Italy](#)
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[Salute Donna Onlus](#)
[Health: An Assesst and a Right That Needs to be Protected and Promoted](#)
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FedEmo Onlus (Federazione delle Associazioni Emofilici Onlus) Punto-e 2019 - 2020
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National Cancer Society of Malaysia City Cancer Challenge And Engagement Opportunities For Patient Organisations: A Case Study Of Greater Petaling, Malaysia
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MEXICO

Asociación Mexicana de Lucha Contra el Cáncer & Sintra, Adela Ayensa Together Against Cancer
Engaging in Healthcare Transformation

PERU

Asociación de Contribuyentes del Perú The Power Of Data: Building Patient's Participation In Healthcare Transformation Through Evidence And Data
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EVITA The Underestimated Burden Of Hereditary Cancer
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PAG Life with Challenges Mental Health Care As A Vital Part In The Holistic Care For Patients And Families With Rare Diseases
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Lymphoma Patient Association LIPA Lymphoma - One Name Many Faces, Power Of Data And Evidence Based Advocacy
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SLOVENIA

Spomničica – Alzheimer Slovenia In The Rhythm Of The Human Brain
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Multiple Sclerosis South Africa Multiple Sclerosis
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SWEDEN

Swedish Hemophilia Society To Live with Haemophilia: Quality of life study - Sweden
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Formosa Cancer Foundation Patient's Awareness and Involvement in Clinical Decision Making in the Era of the Advancement on Treatment Landscapes
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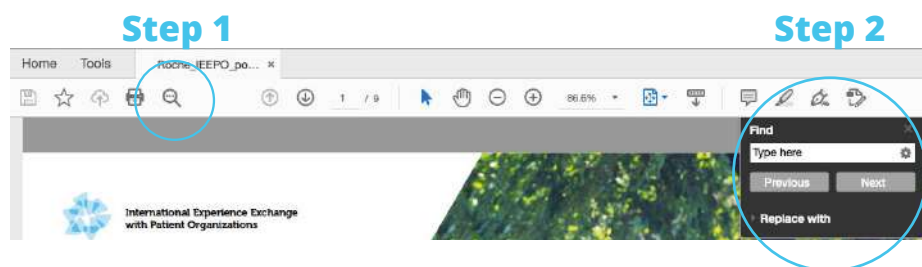
Hope Foundation For Cancer Care Using (HOPE Passport) as PHC tool to enhance cancer patient's self-management
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TURKEY

Kanser Savaşçıları Cancer Survivors Association
Engaging in Healthcare Transformation

Pembe İzler Pink Route
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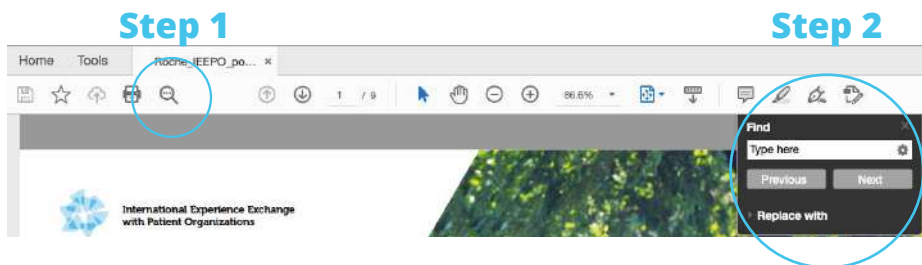
Autism Science Foundation

Data Harmonization Across Genetic Conditions Associated with Autism
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LUNgevity Foundation

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ONCOLOGY

Breast Cancer

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Hematology

La Lampada di Aladino
Voices Matter
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Hereditary Cancer

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The Underestimated Burden Of Hereditary Cancer
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Lung Cancer

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Lymphoma

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Pan-Oncology

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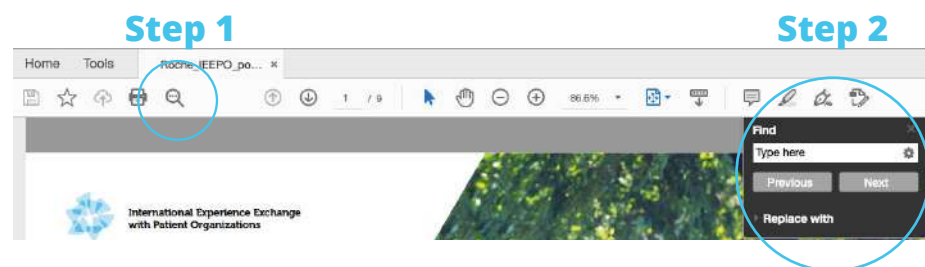
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Using (HOPE Passport) as PHC tool to enhance cancer patient's self-management
Digitalisation of Healthcare

New Sunshine Charity Foundation
Patient Involvement Decision Making: Chinese Practice on Childhood Cancer Comprehensive Control
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RARE DISEASE

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Chinese Angelman Syndrome Organization
One For All and All For One - The Long Term Doctor- Patient Alliance for Chinese Angelman Syndrome Patients
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Duchenne Muscle Dystrophy

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Contributions Of Brazil Huntington's Association (ABH) To The Registration Of Cases Of Huntington's Disease In To The Registration Of Cases Of Huntington's Disease In Brazil
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Spazio Huntingdon - A Place for Children
The Power of Data

Pan-rare disease

The Illness Challenge Foundation
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Mental Health Care As A Vital Part In The Holistic Care For Patients And Families With Rare Diseases
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Spinal Muscular Athrophy

SMA Benimle Yürü
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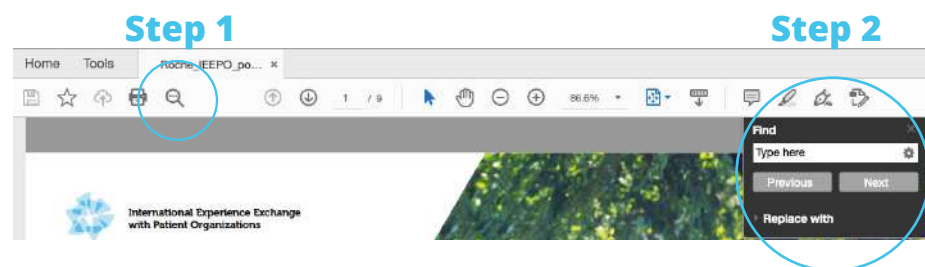
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Multiple Sclerosis
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Eliminating Disparities In Precision Medicine Through A Patient-provider Intervention
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Vitaly Matushenko
The Power Of Data
RARE DISEASE, SPINAL
MUSCULAR ATROPHY
Ukraine

The specificity of collecting PROMs by “patients driven” registries for rare diseases vs “doctors driven” on example of Ukrainian Registry for Spinal Muscular Atrophy

V. Matyushenko¹, A. Shatillo²

¹Kharkiv Charitable Foundation “Children with Spinal Muscular Atrophy”, Ukraine,
²Institute of Neurology, Psychiatry and Narcology NAMS of Ukraine
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Non-governmental patient-driven Children SMA Foundation founded by parents of the children with Spinal Muscular Atrophy, dedicated to improving the quality of life for people living with SMA in Ukraine and supporting of scientific developments.

Keywords: spinal muscular atrophy, rare disease registries, TREAT-NMD, CSMA, universal registry platform, URP

INTRODUCTION

The Ukrainian SMA Registry refer to the disease-specific geographically defined population and aim to register all cases in population; uses observational study methods to collect uniform data (clinical and other) to evaluate specified outcomes for a population in Ukraine and serves scientific, clinical, policy purposes, although, a utility of the Registry is mostly called-for internationally rather inside.

METHODS

A minimum common data set and expanded core data set (from 2017) according TREAT NMD Consortium agreed entries as well clinical are collected by “patients driven” technology since 2004. Involvement of stakeholders such as patients, researchers and clinicians in the design, analysis and governance of the Registry was used to address the complexity and scarcity of knowledge on SMA.

Patient-Reported Outcome Measures

PROMs can be applied to obtain data from the patient’s perspective. The data can guide in making decisions about different clinical inputs and for monitoring the outcomes of specific interventions, provide a baseline assessment of the health status, PROs offer pharmaceutical companies the chance to quantify the patient perspective on a disease or treatment. They are increasingly being used throughout R&D, shaping drug development, regulatory submissions, through discussions with payers, new models of reimbursement. A number of organizations and industrial players have increased their efforts to develop relevant outcome measures for common disease studies or make recommendations on ways to improve patient-relevant outcome measures used in patient-centered outcome research.

RESULTS

Using data sets for scientific purpose as well worldwide geographically differences of published recommendations of standards of care in TREAT-NMD Alliance publication were showed. These common and specific data sets are enable to comparison across Ukraine and internationally. This goal was achieved through easy access to the self-report method to input data. A comparative analysis with the method of entering data by the doctor was carried out. Disadvantages and benefits for patients driven” and “doctors driven” were assessed.

CONCLUSION

An amount, frequency, accessible of data collection shows the high level of sustainability, useful to share patient information in the form of “patients driven” registries to increase the overall patient cohorts when a natural history, clinical, patient-centered outcomes and new technologies can be statistically assessed. An attraction of patients’ organizations to drive RDs registries is more than desirable, but needs to financial and legal support from all interested parties as the State as well pharmaceutical companies. Tools for incentive are valuable.

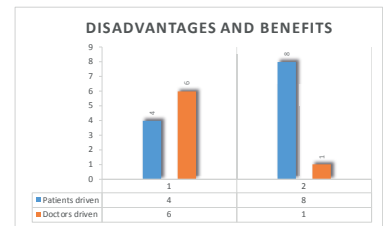
REMARKS

Since 2004, the Registry registered 428 patients from all regions of Ukraine and partially around from countries without own registries. As of February 2020, the registry contain 257 active records. The number not include 37 patients who relocated from Ukraine, 41 patients who died, 77 citizens of other countries, and 17 patients whose information has not been updated for 12 months or more (loss of contact).

ORIGINAL ITEMS	EXPANDED ITEMS
Personal data, demographics	Date&cause of death
Wheelchair use	Clinical observations incl. contractures
Clinical diagnosis	HCP details
Genetic test result	TV&NIV use
Best & current motor function	Airway clearance/secretion mobilisation
Feeding function	PVC results
Scoliosis surgery	Medications&disease-modifying therapies
Pulmonary function	Therapeutic interventions
Family history	Allopathic drugs
SMA type	Hospitalisations&co-morbidities
SMN2 Copies	≥ 1 validated motor outcome measure
Module of PROs*	Electrophysiology&biomarkers taken
Social performance/satisfaction	PRO:
Fatigue	Clinical Global Impression of Severity (CGI-S)
Activity participation	Total Global Impression (TGI) according to patient/parent
Emotional health	
Pain	

* under development

DISADVANTAGES AND BENEFITS	
“PATIENTS DRIVEN”	“DOCTORS DRIVEN”
<ul style="list-style-type: none"> The need to control of filled data; the need to have a consultant for on-line QA; the need regular missing data reminders; the need of incentive to update of data. 	<ul style="list-style-type: none"> Limited access to the registry due to the need to schedule a visit; mostly hard logistics; severity of condition for assessment during visit; limited staff of involved doctors; doctors qualifications; the need financial incentive for a doctor or staff for data entry.
<ul style="list-style-type: none"> 24/7 access to personal data; no need for logistics; opportunity to receive an online consultation; free recruitment of new members (no bureaucratic enrollment required); more trusty between parents than doctors; the ability of curators to create of update requests at any frequency; Curator Query Control; network registry structure with regional curators. 	<ul style="list-style-type: none"> Quality of data



ACKNOWLEDGMENTS

CSMA grateful for parents taking part of the Ukrainian Registry.

Partial financial support for developing universal registry platform (URP) provided by TREAT NMD Consortium.

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BACK

Data Harmonization Across Genetic Conditions Associated with Autism



A.K. Halladay^{1,2}, H. Grosman^{1,3}, J. Acampado⁴, J. Tjermagel⁴
¹ Autism Science Foundation, ²Rutgers University, ³Mount Sinai School of Medicine, ⁴Simons Foundation Autism Research Initiative



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Autism Science Foundation

Alison Singer

The Power of Data

NEUROSCIENCE, AUTISM SPECTRUM DISORDER

USA

Background

- Advances in genetic testing have resulted in the discovery of rare genetic variants that increase the risk for autism spectrum disorder (ASD) and related neurodevelopmental disorders. Understanding ASD with a distinct genetic etiology is critical to developing interventions for both syndromic and idiopathic ASD.
- Families affected by these genetic conditions have established Patient Advocacy Groups (PAGs) that have developed and maintained research registries that provide researchers important data, communicate information to families, and help with research study participation.
- These PAGs have come together to form a consortium to address common issues, including harmonizing registry-based data, in a group called AGENDA (Alliance for the Genetic Etiologies of Neurodevelopmental Disorders and Autism).
- The United States Food and Drug Administration (FDA) states that study data standards are an efficient approach to exchange clinical data between computer systems, and a proven methodology to organize data. Commercial Investigational New Drug (IND) applications must be submitted in data formats supported by the FDA.
- Study standards have been developed by the FDA and the non-profit Clinical Data Interchange Standards Consortium (CDISC), and other sponsors. The FDA supports efforts to create therapeutic area standards.



Objective

- The goal of this project was to create a resource for the autism research community that condensed key questions across the registries of PAGs to facilitate research in this area.

Materials and Methods

- In October of 2017, SFARI hosted a meeting of PAGs, industry and researchers to understand the gaps and barriers in utilizing patient registries.
- Participants suggested conducting an inventory of similar and unique questions across registries.
- Advisors were engaged in prioritizing domains of highest immediate interest.
- Data dictionaries were collected from each registry and analyzed to identify similarities between questions and responses.
- Questions from each registry were organized according to corresponding domain, in a similar approach to developing CDISC Study Data Tabulation Model (SDTM) standards for clinical data.
- Potential response formats (i.e. multiple choice, open text) were noted.
- Standardized questions and responses were proposed. For questions, the recommendations were to include the variable name. For responses, the answer code/data type was included.

EXAMPLE:

- "Age at first walking"
- What age did the child begin to walk? (integer response)
- Age when first walked unaided in months (integer response)
- How old was the patient when [walk unassisted]? (int response)

RECOMMENDATION:

- Is the participant able to walk without assistance? (No | Yes | Unknown)
- What was the age in months that the participant first walked without assistance? (integer response)

Question	Response	Variable Name	Data Type
Age at first walking	What age did the child begin to walk?	AGE_FIRST_WALK	integer
Age when first walked unaided	Age when first walked unaided in months	AGE_FIRST_WALK_UNAIDED	integer
How old was the patient when [walk unassisted]?	How old was the patient when [walk unassisted]?	AGE_FIRST_WALK_UNAIDED	integer

Results

- A total of 239 questions were evaluated across 8 registries.
- Two domains were identified in the analysis, Demographics (DM) and Medical History (MH). Within the Medical History domain, three subcategories were created for developmental questions (MH_DEV), neurological questions (MH_NEURO) and pregnancy questions (MH_PREG).
- Recommendations were made to propose standardized questions and responses for the questions analyzed across the 8 registries.

- The final resource can be accessed here: <https://www.gdaac.org/for-scientists>

The content of this poster represents the work and opinions of the patient advocacy group who is the author, and who is responsible for the described activity's compliance with applicable laws and regulations. VERBA number: AM-XX-000002889

Future Priorities and Activities

- Additional domains of interest should be prioritized and standardized.
- A pilot study is recommended to be conducted using the existing resource.
- An initiative to explore governing policies around data, as well as potential collaborations with organizations such as CDISC to create formal standards will convene.

Collaborators and Advisors

The following organizations contributed their data dictionaries for inclusion in this resource. We would also like to thank Ed Cook, Audrey Thurm and Shafiq Jeste for their advice helping to identify scientific and clinical priorities for this first phase.



Acknowledgments

Thank you to Lindsey Carner for her assistance with helping design and format this presentation.



BACK

Evaluation of the work situation of multiple sclerosis patients in relation to edss

IEEPO Poster Presentation - Application



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Name of Patient Group and Presenter

BRAZILIAN ASSOCIATION OF MULTIPLE SCLEROSIS – ABEM
Sumaya Caldas Afif - Government Relations
Jislaine Oliveira da Silva
Dyana Gervana de Oliveira Fernandes;
Thais Mira
Alice Estevo Dias



Topic/Project

Please describe the topic/project you would like to present in a few sentences

INTRODUCTION: Multiple sclerosis (MS) is a chronic, progressive disease of unknown etiology. Due to demyelination that occurs in the central nervous system, its lesions can cause several functional and / or disabling changes. It is estimated that currently in Brazil, its prevalence is 15 / 100,000 inhabitants. In addition, MS is one of the leading causes of physical disability in young adults in Brazil.
GOAL: To assess the labor situation of patients in relation to Expanded Disability Status Scale - EDSS.

Associação Brasileira De Esclerose Múltipla

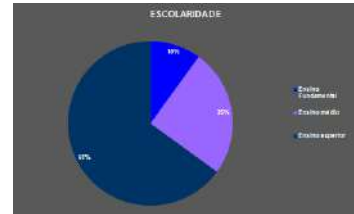
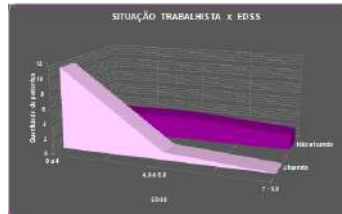
Sumaya Afif

The Power of Data

NEUROSCIENCE, MULTIPLE SCLEROSIS

Brazil

METHOD: Study conducted in a Civil Social Organization in the city of São Paulo, with 20 patients, male and female, aged between 21 and 60 years, covering all types of MS, with EDSS between 0 - 9.5, by applying a questionnaire. Sociodemographic.



RESULTS: The sample consisted predominantly of women, but 40% are male. The types of MS are relapsing remitting (80%), primary progressive (15%) and secondary progressive (5%), with EDSS 0 - 4 (70%); 4.5 - 6.5 (20%); 7 - 9.5 (10%). Regarding education, there is a higher prevalence of higher education (65%). The results obtained through the questionnaire showed that the lower the EDSS (0 to 4.0), the more patients are able to develop work activities (55%). However, only 5% of patients with EDSS greater than 4.0 worked.

CONCLUSION: The progression of the disease has a direct influence on financial and social aspects of the individual's life. Making it necessary for health professionals to reflect more on the incidence of the disease, as well as on the search for treatment innovations.

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 ONCOLOGY, HEMATOLOGY
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Authors: S.Rota¹ - F. Angrilli² - P. Salutarì² - N. Re⁴ - D. Petruzzelli¹ - D. Castelli¹ - R. Bollina³
¹La Lampada di Aladino onlus, Brugherio, Italy e F.A.V.O. - ²Ospedale Civile Spirito Santo, Pescara, Italy
³Oncologia ASST Rhodense, Rho, Italy - ⁴AIPLMC, Milano, Italy

Rationale

The Patient Associations dedicated to blood cancer have grown both in quantitative and qualitative terms. They are made up of people who built their expertise living the experience of the disease: a unique competence that the Italian Health System will increasingly have to take into account. Many of these, however, are small and medium-small in size, dispersed among the different pathologies, sometimes peripheral.

For this reason, within F.A.V.O., it was created the Haematological Neoplasms Group which aim is to establish a network to better understand patients' needs and expectations and to constitute a UNIQUE and STRONGER voice of discussion with institutions and clinicians. This network, which brings together the Blood Cancer Patient Associations, is intended to promote:

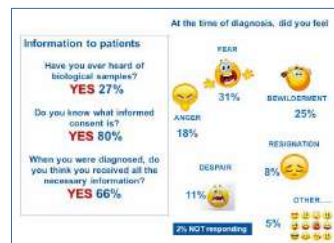
- initiatives to raise awareness of the needs of patients, relatives, caregivers
- investigations, studies and research focusing on the topic of haematological neoplasms and problems related to the needs of patients, family members, caregivers to propose solutions to institutions and decision-makers
- empowerment of patients and training of Association representatives through capacity-building pathways to consolidate advocacy for the patient, family members, caregivers
- exchange of information, experience and good practice
- development of relations with the scientific community of reference
- permanent representativeness towards the institutions

Method

This is how the survey "Voices matter" was initiated, by an online and paper questionnaire, aiming to highlight the gaps in information reported by patients about the disease, the course of treatment and the consequences of a blood cancer on their quality of life. The survey was conducted in Italy to investigate different aspects related to the patient's awareness on the progress of his disease including the psychological-social-economic areas.

Results

- The survey included a population of 850 blood cancer patients: 49.6% men and 50.4% women, in the 30-70 age group, distributed throughout the country (40% in the North, 36% in the Centre and 24% in the South and Islands).
- In terms of disease, 40% were diagnosed with lymphoma, 32% with leukaemia and 16% with myeloma.
- In terms of treatment, duration 31% were diagnosed more than 5 years ago: of these, 76% follow periodic check-ups. 64% are still being treated.
- Interviewees report information/communication gaps. At the time of the diagnosis the reported feelings show great fragility, which leads to think that patients sign the Informed Consent more as a due act than as a fully understood document.
- Another lack of information concerns the world of Associations: 65% of the participants at the time of diagnosis did not know the Patient Associations and only 41% were invited to join them, mainly by haematologists or other patients. The survey reveals that the areas of activity selected and considered the core business of the association are those related to services and bureaucratic practices, followed by psychological and information support on the pathology.



- General Practitioners are perceived as a support figure by just under half of the participants (44%), but only a very low percentage was directed by their GP to a Patients' Association. **A greater synergy between the GPs and the world of Associations would be desirable and would certainly improve the quality of patient care at a territorial level.**

- The Survey finally touches on a delicate and difficult point: the consequences of the disease in the workplace and on the fulfillment of personal aspirations. About half of the patients with onco-hematological disease surveyed have problems in managing their work (48%) and their families (42%) and more than 30% in accessing credit and insurance products.

Conclusions

Today there are about 900,000 people cured of cancer in Italy, and this is a new and extremely important fact because it imposes a new objective on the Patient Associations: to work together to eliminate the barriers that hinder the return of cancer survivors to normal life. From the survey clearly emerges the need to make patients feel useful and considered through a rehabilitation of the person, not only in the injured function, but also psychological, social, work ; it is a right that Patient Associations can and must defend and enforce: this is the commitment and the promise that will guide the future activities of F.A.V.O. Haematological Neoplasms, born to act as a bridge between patients, clinicians and institutions.

info@lampada-aladino.it



BACK

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ACTO Onlus
Nicoletta Cerana
The Power of Data
ONCOLOGY, OVARIAN CANCER
Italy

Ricerca In-Acto

A multicentre, perspective survey about knowledge, attitudes and experience on randomized controlled trials among women with ovarian cancer

Authors: N. Cerana (1), P. Mosconi (2) on behalf of Acto – Alleanza contro il Tumore Ovarico national network
(1) Acto Alleanza contro il Tumore Ovarico Onlus (Milan) (2) Istituto di Ricerche Farmacologiche Mario Negri IRCCS, Milan

BACKGROUND

Despite several initiatives by research groups, regulatory authorities, scientific associations to engage citizens/patients on clinical research, some obstacles still prevent people to participate, chiefly the partial understanding of the concepts related to the proposed study, and the scarce explanations received. The study investigates knowledge, understanding and trust in clinical trials, obstacles and motivation in participation, satisfaction with the information received and involvement of ovarian cancer women on clinical trials.

PATIENT ELIGIBILITY CRITERIA

- Key inclusion criteria**
- Women diagnosed with ovarian cancer at the first follow-up visit and / or the first therapy session
 - Women signing informed consent
- Key exclusion criteria**
- Women not understanding the Italian language
 - Women with life expectancy of less than 6 months
 - Women included in phase 1 studies
 - Women who do not sign informed consent

OBJECTIVES

- Explore**
- knowledge and understanding of a randomized controlled clinical trial (RCT)
 - trust in RCTs
 - obstacles to participation
 - reasons for participation
 - satisfaction with the information received and type of involvement

PARTICIPANT CENTRES

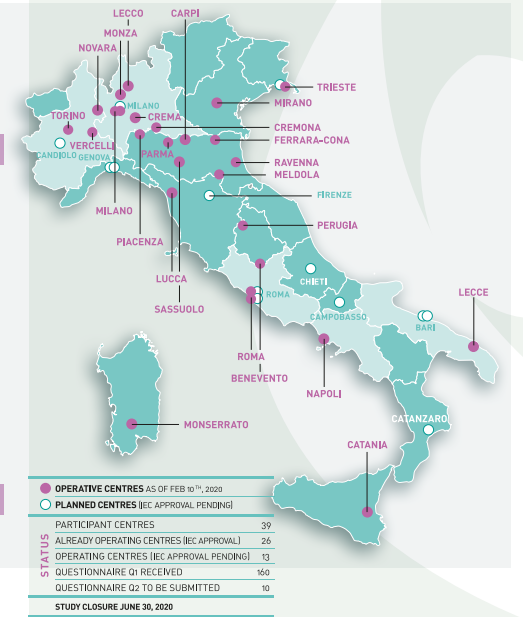
MaNGO (Mario Negri Gynecologic Oncology) and MITO (Multicenter Italians Trials in Ovarian Cancer) groups. 38 centres coordinated by Mario Negri Institute IRCCS.

METHODOLOGY

RICERCA IN-ACTO is a prospective, multicentre study using self-administered questionnaires. Steps are:

- signature of informed consent
- delivery of first questionnaire by the physician of the participating center to eligible ovarian cancer women during the first follow-up visit or during the first therapy session
- mailing of a follow-up questionnaire after 3 months.

The questionnaire was developed starting from a research of literature, and through a validation process by researchers, clinicians and ACTO regional groups (Bari, Campania Lombardia, Piemonte, Roma). Study started in March 2019. It will be completed by June 30, 2020.



RESULTS

The protocol and the questionnaires have been finalised, and submitted to the competent ethics committees. Currently 26 centres started the recruitment after approval from ethics committee.

CONCLUSIONS

The participation of a large number of clinical centres shows the great interest in this topic. Results will contribute to understand knowledge and attitude of women with a history of ovarian cancer as regards clinical studies and will be instrumental in suggesting how to improve the culture of clinical studies and compliance and to implement new communication ways between doctor and patient.

ACTO - Alleanza Contro il Tumore Ovarico
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BACK

Contributions of brazil huntington's association (abh) to the registration of cases of huntington's disease in to the registration of cases of huntington's disease in Brazil

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Maria Aparecida Santos de Souza Alencar
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Associação Brasil Huntington-ABH

Maria Aparecida Alencar

The Power of Data

RARE DISEASE, HUNTINGTON'S DISEASE

Brazil

BACKGROUND

Huntington's Disease (HD) is an inherited neurodegenerative disorder. Despite affecting people all over the world, some countries still have a large gap regarding the diagnosis and consequently the statistical data. While investigation about HD is often in Europe and Asia's countries, data are still very scarce in South America. There are no official statistical data in Brazil. The Brazil Huntington Association (ABH) is the only institution that presents database about HD in this country. ABH is the only institution that presents records, in general, about HD in this country. The main objectives of the association are to provide support and guidance to family members on the several topics related to HD and this is have been done through email, website, telephone and in person for those who can visit to the ABH headquarters in São Paulo city.

AIM

The aim of the present study is presents records about numbers of HD in Brazil, according ABH registers..

METHODS

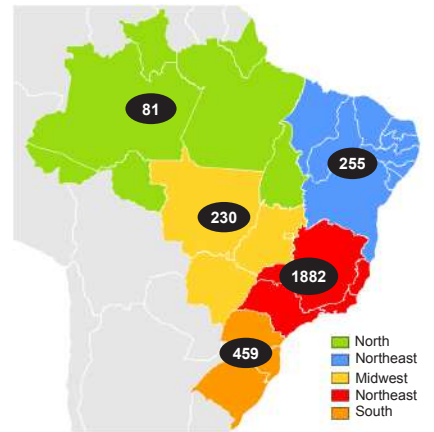
Usually family members know Brazil Huntington Association (ABH) through other relatives, most by the internet (website and social networks) and many are referred by doctors, who know ABH-work and guide family members to receive more information about the disease, care, and so on. The association provides support and guidance to family members on the several topics related to HD and it has been done through email, website, telephone and in person for those who can go to the ABH headquarters in São Paulo. In addition, the association collects data from families that come into contact, feeding its own database.

RESULTS

The Brazilian population is formed by 208 million inhabitants, and it is estimated that there are 13,000 to 19,000 carriers and 65,000 to 95,000 people at risk for HD (70/100 per million). Currently, ABH has 2,942 families registered, which means an approximately three times greater number of patients and carriers of the altered gene, since there are several members affected by family. However, three groups with a high prevalence of HD cases stand out, which are located in Feira Grande / AL, Senador Sá / CE and Ervália / MG.

Estimate of HD prevalence in the brazilian population	
Current estimate of the country's population:	208.000.000 inhabitants
Prevalence of 70/million inhabitants:	15.275 people with the HD gene
76.375 people at risk	(5x the number of people with the gene)
Number of registrations at ABH until December 31, 2019:	3055
ABH register:	20% of the estimated number of cases

Distribution of HD cases by region



PICTURE 01

CONCLUSIONS

Brazil Huntington Association (ABH), based on information from family members, is the only institution that collects data related to Huntington's disease in all states of Brazil.

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BACK

Lymphoma - one name many faces, Power of data and evidence based advocacy

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Lymphoma Patient Association LIPA

Maja Kocic
The Power of Data
ONCOLOGY, LYMPHOMA
Serbia



Established in 2006 Lymphoma Patient Association LYPA is the national, non-profit, volunteer-based association dedicated to support lymphoma patients and caregivers. Our work covers a broad range of services including printed and digital patient friendly material, a complete website with detailed information, educating videos, an exchange forums and webinars, workshops, conferences. Our mission is very simple to improve the quality of life of patients affected by CLL and lymphoma by providing the best information education and support, better access to both, standard and innovative treatments, clinical trials and care.



- In Serbia every day 3 persons find out that they have lymphoma.
- It's supposed that the number of patients is two or three times larger comparing with the number of the diagnosed.
- 20% of lymphoma patients are given the diagnosis without mentioning the word "cancer"!
- Almost 100% of diagnosed prefer to be fully informed about disease, treatments and side effects directly by doctors.
- 55% of population have never heard of lymphoma.



Survey "Lymphoma Care in Serbia- what is missing"

What is not measured has no chance to be improved!

Your experience matters!

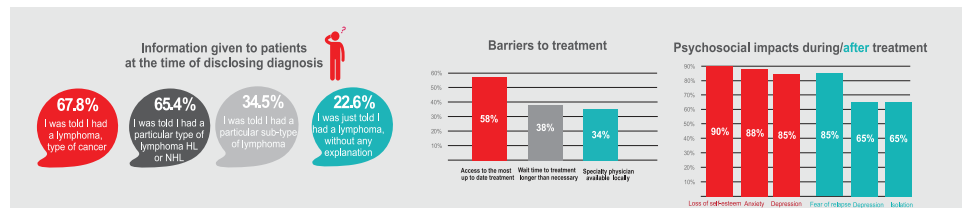
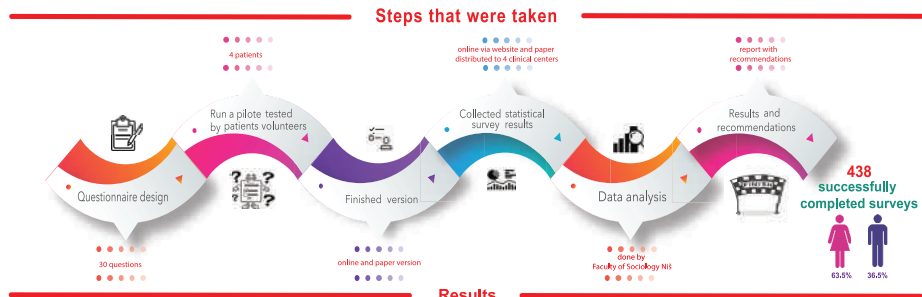
Transforming outcomes together

Why a survey?

- To better understand issues and challenges that lymphoma/CLL patients in Serbia face
- To improve access to novel and standard treatments
- To develop own report by highlighting the things important from the Serbian patients point of view

We examined the following issues:

- To what degree have patients been made aware of their diagnosis, subtype, treatment options...
- How are patients being affected by treatment?
- Have HCPs been effective in providing patients with information and support?
- Barriers to receiving appropriate treatment
- Psychosocial concerns of Lymphoma patients after treatments



Success story not just a paper

Problems that emerged as the pre-eminent and burning during and after treatment are associated with physical, functional, psychological and emotional wellbeing, Quality of life. It's not just a matter of clinical outcomes and goes far beyond the final result of a cancer treatment and involves several aspects of daily life that must be tracked. Survivorship requires as much attention from patient and HCPs as the treatment of cancer.

We run a pilot project in Nis, called Patient Concerns List, with the main aim to identify and emphasize concerns that patients would like to discuss during their check-ups. What comes out of this is the LIMFOM APP the first-ever android application in Serbian dedicated to lymphoma and CLL patients focused on educating and improving patients QoL by tracing 20 symptoms on a daily basis creating a pdf file to share with the doctors.

Despite being one of the most common cancer in Serbia, lymphoma is neither well-known nor easily understood or recognized. As one of the main information provider LYPA has improved its approach to accessible and understandable information in order to ensure our materials and actions meet the needs of patients and their family members. Our main goal is to provide our community with relevant information through education, printed and digital material, webinars, trainings, conferences.

LYPA joint forces with three patient groups forming **Initiative for Innovative Approach to Improving Access to New Medicines in Serbia** representing over 700,000 patients suffering from rare tumors, diabetes, CML and lymphoma.

The initiative hired an expert on pharmacoeconomics who created a **Pragmatic Value Assessment (PVA) System** a straightforward scoring system which covers all relevant aspects of the reimbursement decision-making process.

The proposal was presented to the Minister of Health and denied. We enhanced campaign visibility by working with the media and had supportive coverage in the press.

A panel discussion entitled "How close are we to having up-to-date healthcare in Serbia?" was used to discuss how to implement the PVA into the existing system.

A case study entitled "Modernising the Serbian Health System" was published in The Economist and was sent to all stakeholders.



We are about to run a patient helper project that would be the initial basis for patient-relevant outcomes registry

www.lipa.org.rs
www.bloodcancer101.org.ra

You are not alone!

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Instituto Oncoguia

Luciana Holtz

The Power of Data

ONCOLOGY, LUNG CANCER

Brazil

Lung Cancer Monitoring Platform (Lung Cancer Radar)

NAME OF PATIENT GROUP: **institute Oncoguia**
 CONTACT: **Luciana Holtz** lucianaholtz@oncoguia.org.br
 DESCRIPTION: The initiative Lung Cancer Radar provides information about lung cancer patients in Brazil, including data about staging at diagnose, incidence, mortality and other data and numbers related with brazilian laws. All data published at the online interactive platform comes from public sources, with previous analysis of a health specialist. The objective of this initiative is to raise awareness on lung cancer as well as provide a tool with useful information for public decision makers and other key stakeholders.

PROJECT: **LUNG CANCER MONITORING PLATFORM (LUNG CANCER RADAR)**

THE LUNG CANCER RADAR - METHODOLOGY

For the current study Oncoguia has chosen public data sources provided by DATASUS (SIASUS, SIHSUS), INCA (RHC) and GLOBOCAN. At DATASUS and INCA websites, we have used all lung cancer data linked to ICD C34. At GLOBOCAN website Oncoguia has selected all data linked to the word "lung".

THE LUNG CANCER RADAR LAUNCH: august, 2019
UPDATE CYCLE: every 3 months / once a year (depending on the information)

CONTENT: **LUNG CANCER SCENARIO**

GLOBAL 2018
 INCIDENCE: 2.093.867
 MORTALITY: 1.761.007
 IN INCIDENCE* AND MORTALITY

IN BRAZIL 2018
 INCIDENCE: 34.511
 MORTALITY: 31.856
 IN INCIDENCE* AND IN MORTALITY

Legend: 1B BREAST CANCER, 2P PROSTATE CANCER, 3C COLORECTAL CANCER

REGISTRIES FOR ADVANCED STAGE (III AND IV)

STAGE X PROBABILITY OF NOT SURVIVING IN 05 YEARS (GLOBAL)

IIIA	64%
IIIB	74%
IIIC	87%
IVA	90%
IVB	100%

HOSPITALIZATION COSTS

PERIOD	TOTAL AMOUNT (R\$)	HOSPITAL (%)	ICU (%)
TEN-YEAR PERIOD	R\$ 339.203.737,56	84,9	15,1
2016	R\$ 40.087.411,04	85,7	14,3

60-DAY LAW RANKING (VIOLATION)

State	Ranking
SE	100%
PA	35%
CE	35%
BA	35%
MS	34%
TO	34%
AM	30%
MA	30%
SC	30%

PATIENT JOURNEY / ACCESS TO TREATMENT

60-DAY LAW VIOLATION: 29,83%

OTHER INFORMATION AT LUNG CANCER RADAR

INCIDENCE | MORTALITY | SURGERY | RADIOTHERAPY | CHEMOTHERAPY

VISIT OUR WEBSITE: WWW.ONCOGUIA.ORG.BR/RADAR



BACK

Spazio Huntington - A Place for Children



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Fondazione LIRH
Marta Tommolini
The Power of Data
RARE DISEASE, HUNTINGTON'S DISEASE
Italy

Barbara D'Alessio (LIRH Foundation, Rome) - Alessandro Capuano (Bambino Gesù Pediatric Hospital, Rome)
Ferdinando Squitieri (Casa Sollievo della Sofferenza Hospital, San Giovanni Rotondo & Rome) - Marta Tommolini (LIRH Foundation, Rome)



Huntington's Disease
Huntington's disease is a genetic, rare, hereditary, neurodegenerative disorder that mainly affects the nervous system. The complexity of the disease is due to the fact that it acts simultaneously on several levels: **involuntary movements** (like an uncontrolled dance, which is why it is also called chorea, from the Greek "dance"), **loss of cognitive capacities** and **psychiatric disorders**. Therefore it manifests itself with different patterns varying from person to person, even within the same family: "The same cause, different faces of the disease". This makes it particularly difficult to recognize and treat it properly. To date, the disease can only be treated symptomatically. No cure has yet been found that would lead to recovery, slow down its progress or prevent its onset.

Huntington's disease in children
Huntington's disease can rarely begin in childhood or adolescence, well before the age of majority. In this case, clinical signs can be very different from the adult form. Thanks to recent discoveries, the scientific community recognizes the paediatric variant as the "true" juvenile form, being clinically and biologically different from that of the adults. (Biological and clinical manifestations of juvenile Huntington's disease: a retrospective analysis. Lancet Neurol. 2018 Nov - Squitieri F. et al.)

Fondazione Lega Italiana Ricerca Huntington (LIRH)
LIRH is the largest Italian non profit organization completely focused on research, care and education on HD and Juvenile onset HD. It was founded and it is runned by researchers and family's members together. LIRH aims to guarantee to people affected by Huntington's disease, the opportunity to access innovative therapies and receive adequate clinical and psychological assistance. LIRH follows with special attention the evolution of scientific research on paediatric Huntington's disease (PHD) and actively collaborates with international organizations and working groups aimed at developing a potential cure for this variant of the disease, as well as for the adult form.



From Left: Dr Simone Migliore (CSS), Dr.ssa Federica Gaziola and Dr. Alessandro Capuano (Bambino Gesù), Maria Gabriele (LIRH), mothers, grandmothers and children. Dr. Ferdinando Squitieri (CSS/LIRH)



Spazio Huntington: A Place for Children
Today, more than ever, the study of Huntington's disease in its pediatric form appears to be important since the regulatory authority, for the first time, has shown interest in involving also minors in clinical trials. For this reason, The Foundation has promoted a specific project for Huntington's disease in children, in partnership with the Children's Hospital Bambino Gesù. For the first time, experienced Huntington neurologists and pediatric neurologists are working together to give hope to even the youngest HD patients.

- Objectives**
- ✓ To contribute to a better knowledge and understanding of pediatric HD
 - ✓ To get in contact with those families whose children are, or could be, affected by HD
 - ✓ To give them the best possible care and hope for the future
 - ✓ To collect data for research purposes

Methods
We have launched a partnership with **Bambino Gesù**, one of the most important and internationally recognized Pediatric Research Hospital. The HD and JoHD experts (Dr. Ferdinando Squitieri and his team) work in a close collaboration with Bambino Gesù Pediatric Hospital neurologists and child psychiatrists (Dr. Alessandro Capuano and his team), under the coordination of LIRH Foundation team. The LIRH headquarters – which is not a hospitalized environment - is the place where HD families with children meet; children can play and have fun; researchers and professionals monitor and collect information on children; LIRH staff look after families and children.

Achievements
Spazio Huntington was launched in September 2019. Since then, we already got in contact with about 30 minors and their affected/at-risk parents.

We believe *Spazio Huntington* may represent a concrete way to break the wall of parents' fear and to effectively face the most aggressive and overlooked HD variant. We aspect this initiative to have a broader impact on the disease's knowledge at a national and international level.

Fondazione Lega Italiana Ricerca Huntington
Via Varese, 31 - 00185 Rome info@lirh.it www.lirh.it



BACK

I Want More - The Demands of Women for the Care in the Breasts Units



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Europa Donna Italia

Laura Pinnavaia

The Power of Data

ONCOLOGY, BREAST CANCER

Italy

«I WANT MORE»

The demands of women for the care in the Breast Units

An Europa Donna Italia (EDI) project to promote the completion of the Breast Units in Italy and ensure their monitoring. **3 phases:**

- National survey** of a sample of **500 patients** from all Regions to verify the perception of the quality of breast cancer diagnosis and treatment pathways and selection of the **10 main patient requests**
- Social campaign** conducted by EDI ambassadors and a group of influencers to gather consensus on the 10 requests with the participation of the 150 associations of the EDI network - over **230,000 people reached**
- Press conference** at the Senate in Rome and presentation of the 10 requests to the representatives of the **Institutions** with the presence of lay and trade **media**



The survey returned **10 priorities:**

- 1) More access to breast units:** 1 out of 3 interviewees report not being treated in a specialized center
- 2) Need for shorter waiting lists:** more respect for waiting times established by law
- 3) More information on side effects:** 1 in 4 did not receive enough information on the side effects of chemotherapy and radiotherapy, 1 out of 3 were not informed about the effects of hormonotherapy
- 4) More support for lymphedema:** 1 out of 6 would have liked more support from physiotherapist or physiatrist after mastectomy
- 5) More psychological support:** insufficient according to 2 out of 3 interviewees
- 6) More genetic assessment:** 1 in 4 patients was not asked any questions relating to genetic assessment
- 7) More presence of plastic surgeon:** almost half of the patients operated had to undergo mastectomy. Therefore the plastic surgeon should be an integral part of the Breast Unit
- 8) More assistance in the follow up phase:** 1 out of 6 patients had difficulties in following the visits schedule due to organizational problems of the hospital
- 9) More continuity of care:** only 6 out of 10 patients completed treatment in the same hospital
- 10) More preservation of fertility:** 1 in 4 young patients was not informed about the possibility of preserving fertility.

RECOGNITION ON THE QUALITY OF CARE
based on **PATIENTS** needs

RAISE AWARENESS
In the public about patient needs and the value of the quality of care and early treatment

OBTAIN FROM INSTITUTIONS
targeted interventions to ensure the presence of **Breast Unit** over the country and the monitoring of patients access to **early treatment** and to **appropriate therapeutic pathways**

GOALS & TARGETS

REQUESTS TO THE INSTITUTIONS:
To accelerate the **COMPLETION** of the **BREAST UNITS'** development, to Start a constant and systematic **MONITORING**

- 10 PRIORITIES FROM THE SURVEY**
- MORE**
-
- 1) Access to breast units
 - 2) Shorter waiting lists
 - 3) Information and support on side effects
 - 4) Lymphedema prevention and treatment
 - 5) Psychological support
 - 6) Genetic assessment
 - 7) Plastic surgeon presence
 - 8) Assistance in the follow up
 - 9) Continuity of care
 - 10) Preservation of fertility



BACK

Patient's Awareness and Involvement in Clinical Decision Making in the Era of the Advancement on Treatment Landscapes

Jane Tsai, M.Ed.,
Ing-Gine Ma, Zoya Yu, Esther Lai



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Formosa Cancer Foundation
Jane Tsai
The Power Of Data
ONCOLOGY, PAN-ONCOLOGY
Taiwan

Introduction

Since the development on genomic medicine and precisionized oncology has greatly advanced in the past years, the treatment outcomes and quality of life for cancer patients have been remarkably improved. The advancement of treatment landscape not only brings new hopes to patients and their families but also generates an urgent need for patients and their family members being more willing to know if any innovative treatment can benefit to their survival and quality of life.

Cancer patients are often confronted with a series of complicated treatment choices and decisions. In Asian cultures, the physician was always regarded as a highly professional personnel with an authority figure. Patients are often in a mindset that they have to respect physician, they better not to challenge physician's authority by talking less or avoiding asking too many questions during clinic visits. In the era of the advancement on cancer

treatment, it has increasingly raised patient's awareness to be more involved in their clinical decision making. Thus, being well informed and included in the decision-making process together with physicians becomes a very important concern. Patient's role may shift from being a passive recipients of treatment plan to being a proactive role in their treatment decisions and will want to take more responsibility on their disease management.

Purpose

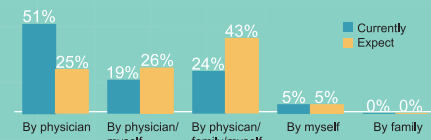
In order to address this issues, the Formosa Cancer Foundation conducted the online survey in October, 2019 to better understand patients' concerns and expectations in clinical decision making. The survey also wants to find out if patients are satisfied with the current decision-making style as well as to learn the possible impact when cancer patients are engaged in their making treatment decisions.

Methods

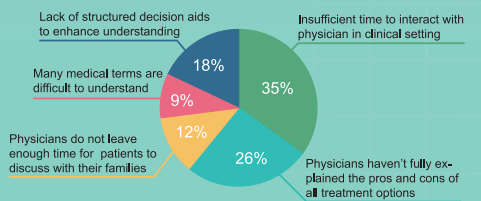
A total of 389 cancer patients and survivors participated in the survey. The survey contained closed- and open-ended questions, which gave the patients a chance to express their opinions. 70% of the respondents were female and the age ranges from 21 to 80.

Patients' current status vs expectations in clinical decision-making

What is the way that your clinical decisions have been made currently?
What is the way that you expect to make your clinical decision?

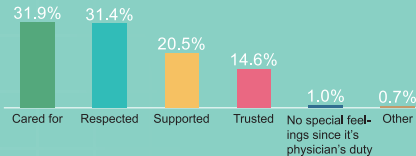


What makes patients feel dissatisfied during current decision making process



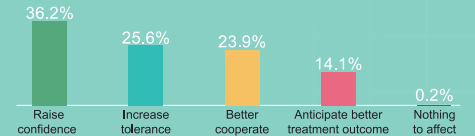
Patients' perceptions when being involved in clinical decision-making

How do you feel when physicians are willing to explain the risks and benefits of available treatment options for you and engage you in the decision making?



The impacts to treatment when patients being engaged in clinical decision-making

If the treatment decision is achieved by you and your physician together, what would be the impact to the treatment?



The top 3 concerns for cancer patients when confronting the evolution of treatment landscape

1. Efficacy

- The best/innovative treatment
- Higher survival rate
- Long-term survival
- Free of disease recurrence
- Cure the disease

2. Cost

- Affordability
- Reimbursed or not

3. Safety

- Less side effects than the existing treatment
- Side effects are more tolerable or clinically manageable

Results

- The younger patients are more likely than those over 65 to want to get involved in clinical decision making. The older patients prefer a more paternalistic style of interaction and think that all the advices from physicians should not be questioned.
- Currently, almost half of the cancer patients (51%) said that their treatment decisions were completely made by physicians. Only about one fourth (24%) of the cancer patients said that their clinical decisions were made by the physicians together with family and themselves. But over two thirds (69%) of them expected and preferred their treatment decisions could be made by physicians together with family and themselves.
- The top 3 concerns for cancer patients when confronting the evolution of treatment landscape are efficacy, affordability and side effects.
- Patients being engaged in the clinical decisions makes them feel more cared for(31.9%), respected(31.4%), supported (20.5%) and would lead to raise confidence(36.2%), to increase tolerance to treatment(25.6%) and better cooperate with physician(23.9%).

Conclusions

- The evolution of the treatment landscape brings new hopes to patients and their families that their awareness of being willing to engage in clinical decision making is remarkably increasing.
- There is a gap existing between the current practice in the treatment decision making process and the style patients prefer to have.
- Patients' expectation in clinical decision-making does not mean only providing information to them, they want to better understand the benefits and risks of the treatment options and preferred to make their treatment decisions together with physicians and family members.
- Patients being engaged in the clinical decisions will generate a positive impact that makes them feel more respected, listened to, valued and would lead to raise confidence and enhance the compliance to treatment.
- It requires to create a more friendly environment to engage cancer patients in clinical decision-making by giving sufficient information/time, additional nurses or administrative staff or decision tools and aids in the clinical settings.
- The affordability and access solution during the evolution of treatment landscape still be cancer patients' critical concern that the acceleration of the regulatory readiness and reimbursement timelines should be considered and developed in advance.

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CSMA Foundation
Vitaly Matushenko
The Power Of Data
NEUROSCIENCE, SPINAL MUSCULAR ATROPHY
Peru

The Power of Data: Building patient's participation in Healthcare transformation through evidence and data

jibeteta@tucontribuyes.org

The decisions that policymakers take should be founded in information

The data provide insights about the problem and enable us to do analysis about: the causes, the solutions, and their implementation



The close and continuous work of ACP with patient associations has permitted collect the main problems that affect Peruvian patients

1 In 2017, ACP identified the lack of transparency in the actualization of the National Formulary for Essential Medicines (PNUME), and the absence of civil society in this process

2 To address this, ACP conducted an analysis of the Peruvian regulatory framework and a comparative analysis of this process in other countries in the region and the world

3 With the data collected and its evaluation we prepared a study that was published on our website

4 The evidence allowed us to reach important public sector actors. Among them, the ombudsman, with whom we met together with the patient associations to present our findings. We also reached congressmen, who appreciated the importance of the participation of patient associations in the PNUME update

5 In June of 2017, a lawmaker presented the project of law N° 1711-2017, which proposes to include the participation of civil society and forces the Health Ministry to pre-publish it for 60 days to get opinions from the academy, the private sector and citizens.

6 In October of 2018, it was approved unanimously in the Health Commission of the Peruvian Congress. In September of 2019 was approved unanimously in the plenary session of the Congress

This represents a great victory for the Peruvian patient associations and shows the importance to promote public policy reforms based on evidence and data



BACK

Incorporating Colorectal Cancer Patient Values and Preferences Into Health Technology Assessment (The "PVP" Project)

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Colorectal Cancer Canada
Barry Stein
The Power of Data
ONCOLOGY, COLORECTAL CANCER
Canada

COLORECTAL CANCER CANADA

UNIVERSITY OF CALGARY

Dr. Sharlene Gill (BC Cancer Agency); Dr. Winson Cheung (Tom Baker Cancer Centre); Dr. Benjamin Goldberg (Cancer Care Manitoba); Dr. Yoo-Joung Ko (Sunnybrook Health Sciences Centre); Dr. Petr Kavan (Jewish General Hospital); Dr. Bruce Colwell (QEI); Dr. Karen McDonald and Dr. Deborah A. Marshall (University of Calgary); Barry D. Stein (Colorectal Cancer Canada)

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INTRODUCTION AND BACKGROUND

The high cost of cancer drugs has increased pressure on the healthcare system to make better choices and adopt value models when considering drug reimbursement and treatment choices.

While there are many stakeholders in the healthcare system, the perspective of patients is central to the definition of value, yet, it is likely the least understood and most difficult to measure. Attributing what weight patient preferences should carry in health technology assessment (HTA) decisions regarding reimbursement is challenging.

The PVP project will address this issue by developing a framework to objectively incorporate patient values and preferences into the cancer drug HTA decision-making process in Canada since:

- Patients have unique knowledge and perspectives that can influence decisions by pointing out what are the most important aspects or outcomes for them in a specific situation.
- Patient preferences directly impact patient adherence to treatment and can provide a broader view of real-world health evidence. These outcomes can ultimately influence the cost-effectiveness of treatment.
- Patient preferences may serve as an important and evidence-based source of information that can improve the uptake of current health priorities and policy gaps.
- By participating in health decision-making, patient engagement is enhanced which could help to support fair and ethical healthcare decision-making.

CADTH – PAN CANADIAN ONCOLOGY DRUG REVIEW (pCODR)

OBJECTIVES AND RESEARCH QUESTIONS

We are assessing preferences and willingness to pay for CRC treatment for Canadian CRC patients (non-metastatic and metastatic), care givers for CRC patients, and adults from the general population.

Phase 1: Patient preferences will be measured and the value of the attributes of colorectal cancer treatments will be estimated for patients, their families/caregivers, and adults without colorectal cancer from across Canada using a Discrete Choice Experiment survey.

The survey is expected to answer the following research questions:

- How do colorectal cancer patients (early and metastatic) value various aspects of oncology drug treatments when weighing the associated benefits and risks?
- How do values differ based on patients' demographics, quality of life, stage of cancer and experiences?
- What are the relative quantitative weights for the benefits and risks (attributes) of treatment decisions?

Phase 2: The most effective combination of attributes will be determined for cancer patients faced with oncology drug treatment decisions, and a weight will be assigned to those attributes.

Phase 3: Incorporate patient preferences explicitly into decision making, determine methodology to use, what weighting to assign.

PHASES OF THE PVP

SURVEY SITES

- VANCOUVER, BC Cancer Agency
- CALGARY, Tom Baker Cancer Centre
- WINNIPEG, Cancer Care Manitoba
- TORONTO, Odette Cancer Centre, Sunnybrook
- MONTREAL, Jewish General Hospital
- HALIFAX, QEI

SURVEY STAGES

QUALITATIVE WORK TO INFORM DCE
Princess Margaret Hospital to inform the DCE framework, attributes + level development

SURVEY PRE-TEST:
One-on-one interviews with metastatic and non-metastatic cancer patients (n = 5) | Provided updates to Inform Pilot Survey using the patient feedback

SURVEY PILOT TEST:
Survey online sample of (non-metastatic and metastatic; n=30) CRC patients. Ensure attributes, levels facilitate trade-offs among

MAIN SURVEY:
Population groups from the 6 survey sites (n = 1200):
1. Metastatic CRC patients (n = 300)
2. Non-metastatic CRC patients (n = 300)
3. Caregivers (n = 300)

RECRUITMENT AND CONSENT

Oncologist will inform patients in person either at an in-clinic appointment, or virtual appointments (phone or virtual platform). Study Coordinators will speak with the patient immediately following their appointment in person or for virtual recruitment by phone or virtual platform.

Study Coordinator will inform patient about the study and provide a recruitment letter (paper for in-clinic, email for virtual) providing study details, a unique participant identifier and a website address for the online survey and will ask each patient if they would like to take a separate recruitment letter for their caregiver. Consent will be at the beginning of the online survey.

DISCRETE CHOICE EXPERIMENT (DCE)

The risks and benefits of colorectal cancer treatment vary according to the regimen and therefore, patient preferences must be carefully considered.

To establish the value of different aspects of CRC treatment more formally the rigorous economic approach known as DCE is employed.

DCE is a quantitative method used to elicit patient preferences and utility for various health states and/or other nonmarket goods and services, such as health care and to capture the full value of a treatment and the outcomes of treatment not captured by traditional measures.

Key factors about colorectal cancer treatment have been identified for the DCE survey based on qualitative research conducted by University of Toronto and literature review.

By including a cost attribute in the DCE we can estimate the willingness to pay as a monetary measure of the benefit.



Living with a rheumatic disease in Italy



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Associazione Nazionale Persone con Malattie Reumatologiche e Rare - APMARR aps

Antonella Celano

The Power of Data

IMMUNOLOGY & INFECTIOUS DISEASE,
RHEUMATOID ARTHRITIS
Italy



The 12th Annual International Experience Exchange for Patient Organizations 2020 18-19 March 2020

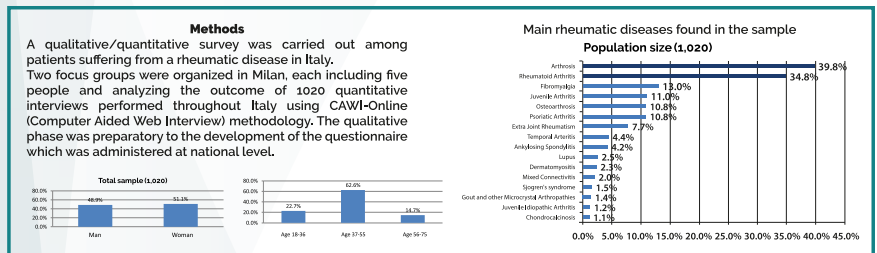
Harnessing the power of data to better understand the experience of an illness

Living with a rheumatic disease in Italy

Authors: APMARR: Associazione Nazionale Persone con Malattie Reumatologiche e Rare - APS
Matteo Santopietro: Managing Director of WeResearch Marketing Research, Marketing Research Division of Baires53 srl

Main objectives of the study

- To evaluate the degree of satisfaction vs. dissatisfaction with the length of the waiting lists to book specialist visits and/or examinations
- Ease vs. difficulty in finding rheumatology specialists
- The relocation of Rheumatology centres in the national territory: if sufficient or insufficient number
- Comfort assessment of the facilities
- Accessibility to facilities: architectural, visual and auditory barriers
- Evaluation of doctor/patient communication
- Access to the medicine
- Knowledge of the facilities/exemptions and ease of obtaining them
- Electronic Health File
- Presence or absence of multidisciplinary outpatient clinics for global patient care (e.g. joint rheumatology/gynaecology)



Main Results

1 WAITING LISTS
How do you rate the average waiting time for visits and/or examinations?

Excessively or fairly long	77%
Standard	23%

2 SPECIALISTS IN RHEUMATOLOGY
How easy is it to find a specialist?

Very difficult enough	37%
Very easy enough	63%

3 RHEUMATOLOGY CENTERS LISTS
How many centres are present in your area?

Completely absent/in insufficient number	69%
In sufficient number	31%

4 COMFORT OF THE FACILITIES
How do you rate your satisfaction with the facilities status (e.g. cleanliness of the premises, free and comfortable seating, toilets)?

Very/quite dissatisfied	21%
Very/quite satisfied	79%

5 ACCESSIBILITY OF THE FACILITIES
Did you find it difficult to access due to architectural barriers?

Yes	40%
No	60%

6 DOCTOR/PATIENT COMMUNICATION
How do you rate the willingness of medical staff to listen?

Very bad/poor	26%
Good/Excellent	74%

7 ACCESS TO MEDICINE
Which is your assessment?

It's easy to find them and have them	80%
It is difficult to find them	20%

8 KNOWLEDGE OF FACILITATIONS/EXEMPTIONS
Are you aware of the facilitations, rights and benefits provided for by Law no. 68/99 (Protected employment categories) and Law no. 104?

Yes	41%
No	59%

9 ELECTRONIC HEALTH RECORD LISTS
Is it active in your region?

Yes	43%
No	21%

10 THE MULTIDISCIPLINARY OUTPATIENT CLINICS FOR GLOBAL PATIENT CARE LISTS (e.g. joint rheumatology/gynaecology clinic)
Have you ever found a shared lab/ambulatory room with a rheumatologist/gynecologist?

Yes	15%
No	85%

TAKE HOME MESSAGE

Two main issues emerged from the survey presented in this poster:
 1) insufficient presence in the territory of Rheumatology Centres;
 2) serious lack of information on the laws and protections provided for patients suffering from a rheumatic disease.
 The scarce presence on the territory of Rheumatology Centres and specialists is the cause of long and exhausting waiting lists, patients are so forced to long transfers and, in their condition, these are reason for further physical as well as psychological suffering.
 The problem of waiting lists is intensely perceived by the patients interviewed and is considered as one major reason of stress, with strong relapses on the psychic condition often causing states of anxiety and depression.

APMARR: Associazione Nazionale Persone con Malattie Reumatologiche e Rare - APS - Italy - Email: info@apmarr.it
 WeResearch - Divisione ricerche di marketing di Baires 53s.r.l. - Via Gaspare Spontini 1, Milano (MI) Italy - Email: info@weresearch.it

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House086
Jin Zhang
The Power of Data
ONCOLOGY, LYMPHOMA
China

Data Initiates Real Changes in the Real World

DATA INITIATES REAL CHANGES IN THE REAL WORLD

UTILIZING GPS DATA LOCALLY

淋巴瘤之家
Lymphoma Association of China

Data is not the end. It is the beginning of identifying needs, improving services, and making difference in patients' real world!



KEY FINDINGS

- ① Patients have heavy economic burden.
- ② Patients need psychological support.
- ③ Patients need information during their whole patient journey, especially the new patients have urgent needs for information.

INFORMATION SUPPORT

A. Use new media to do patient education

- ◆ Wechat groups cover 15+ subtypes
- ◆ Patients and caregivers 20,000+



B. Use handbooks to do patient education



C. Hold world lymphoma awareness day



D. Set up pilot project in lymphoma departments of 33 hospitals in china



E. Promote mutual understanding between physicians and patients



F. Promote mutual understanding between pharmaceutical companies and patients



PSYCHOLOGICAL SUPPORT

A. Launch a new book- living with lymphoma



B. Start 21 days psychological webinar Micro Changes to Happiness



SUPPORT ON REDUCING FINANCIAL BURDEN

STRENGTHEN POLICY ADVOCACY:

- ◆ Tell decision-making departments the true situation of patients with data
- ◆ Participate in meetings related to the development of rare disease catalogues
- ◆ Plan to participate in a HTA international seminar

ESTABLISH CHINA RARE CANCERS PROGRAM:

- ◆ Push more rare cancers in the list of rare diseases
- ◆ Support rare cancers patient groups.

FUTURE DATA COLLECTION OBJECTIVES

Normalization → Dynamic → Fineness



REPORTED OUR RESEARCH RESULTS

We reported our research results with a professional papers published in authoritative magazines



ABOUT US

淋巴瘤之家
HOUSE086.COM

Contact our founder Hongfei: hongfei@house086.com

As the only lymphoma patient supporting group in China, House086 provides lymphoma-related knowledge, information and service to the patients via website and app. The goal of House086 is to enhance patients' confidence in rehabilitation. Hongfei built House086 after he recovered from Hodgkin lymphoma in 2011.

2011



Founded in Beijing

2013



APP was launched

2014



Start video programs- Experts, Patients +Webinar

2015



World Lymphoma Awareness day

2018



Joined GPS

2020



Over 30,000 registered

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PHC Mammography Screening Program



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Dansh Breast Cancer Organisation DBO

Nadia Ryding
The Power of Data
ONCOLOGY, BREAST CANCER
Denmark

PHC Mammography Screening Program

Danish mammography screening program February 2020

- Mammography screening is a public health service
- Mammography screening is voluntary and free of charge in Denmark
- Age >50 - <69
- Mammography screening offered to all women in the defined age group every 2 years
- Triple Test: Mammography, ultrasound and examinations by a doctor/palpation

Facts about breast cancer in Denmark

- 5.000 women are diagnosed with breast cancer every year
- 65.000 women in Denmark live with the diagnosis of breast cancer
- 1.100 women die each year from breast cancer
- DBO (Danish Breast Cancer Organisation) is politically active and works to ensure the interests of Danish women affected by breast cancer.

History

1991
Mammography screening was offered to women aged 50-69 screening, in a few cities in Denmark.

2005

A report from the capital of Copenhagen, shows that for women who were offered mammography screening, the mortality rate decreased by 25 % and for women who actively participated in the mammography screening program, the mortality rate decreased by 37%.

2008

The mammography screening program became a public health service for all women aged 50-69 to participate in the screening program

2020 May

Reassessment of mammography screeningsprogram

Benefits (of screening)

- Early detection breast cancersurvival increases
- Reduced mortality due to breast cancer (30-50%)
- National screening also promoting awareness of breast cancer risk
- National screening provides a high quality diagnostic service

Draw backs

- Over-diagnosis and over-treatment
- False reassurance in false negative cases
- Anxiety and harms in false positive cases
- Radiation exposure

Debate

False Positive: Do women react negatively when they are false positive and if...
How do they react.

Therapy: Are women with a false positive result offered any help?

Age criterion: Extend the age criterion and offer the screening program for women aged?

- > 40- <69
- > 40- <74
- > 50- <74

Personalise programme: Personalise the mammography screening program according to high and low risk?

- overweight
- highly educated women
- alcohol
- smoking

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One For All and All For One - The Long Term Doctor-Patient Alliance for Chinese Angelman Syndrome Patients

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Chinese Angelman Syndrome Organization

Xue Zhang
Engaging in Healthcare Transformation
RARE DISEASE, ANGELMAN SYNDROME
China



Angelman Syndrome (AS) is a rare neurogenetic disorder that affects approximately 1 in 15,000 people – around 500,000 individuals worldwide. Children and adults with AS typically suffer from balance issues, motor impairment and debilitating seizures. The sadness reflects from some individuals never walk; most individuals are unable to speak or construct phrases. Indeed, disrupted sleep cycles also can be a challenge to the AS individual, which impact on caretaker(s). Individuals with AS require continuous care, and are unable to live independently; however, they do have an average life expectancy compared with healthy individuals.

A group of families from China come together founded Chinese Angelman Syndrome Organization (CASO) since 2011. The goal of this organization is to increase awareness of Angelman Syndrome, to help and support AS children and families. Consequently, these social events could promote related primary research interests to enhance the understanding of AS, clinical trials to explore the new treatment and cross-disciplinary collaboration.

1. Education-wise:

Published the first Chinese and English subtitles video of AS in China;
Released AS Medical Rehabilitation Feeding Guide;
Issued 5,000 feeding manuals and over 10,000 brochures on the general knowledge of AS diseases;
Broadening awareness covering hospitals, Government Federation of Disabled Persons, and maternity and child care hospitals all over the country;
In December 2018, CASO promoted the establishment of Green Visiting Channel network covering 11 national top-level hospitals.

2. Research/Drug Development engagement:

Voluntarily organized and participated in the AS research project of Professor WANG Yi's team in Children's Hospital of Fudan University Shanghai, with more than 150 patients participating.

3. Events:

6 annual Family Conferences and free consultation held with Children's Hospital of Fudan University Shanghai;
4 Christmas parties for all families online to showcase AS patients' capability;
4 annual trips designated for AS families.

4. Knowledge centre establishment:

Build up knowledge centre through WeChat group to provide guidance and support to families, 14 AS classes were held, contents covered feeding, epilepsy treatment, rehabilitation training and psychological counselling for parents.



Wechat Official Account



sina weibo

Email : angelman225@126.com
QQ Group : 天使很快乐 203464179
Facebook : Chinese Angelman Syndrome Organization
<https://www.facebook.com/ASF.china>

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City Cancer Challenge And Engagement Opportunities For Patient Organisations: A Case Study Of Greater Petaling, Malaysia


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National Cancer Society of Malaysia
Murallitharan Munisamy
Engaging in Healthcare Transformation
ONCOLOGY, PAN-ONCOLOGY
Malaysia

Murallitharan M*, Mandy Thoo*, Low KY*, Saunthari S*, Nur Aishah Taib*
*National Cancer Society of Malaysia ; *University of Malaya



What is the City Cancer Challenge?


- A global initiative to support cities around the world as they work to improve access to equitable, quality cancer care.
- Launched in 2017 by the Union for International Cancer Control, City Cancer Challenge (C/Can) is a stand-alone foundation working in 9 cities today
- The C/Can model targets cities with a strong need and readiness for improved cancer care.
- Local leaders drive the process from the ground up by selecting a multi-sectoral executive committee in each city, prioritizing specific needs, identifying partners for capacity building, establishing sustainable financing models, and monitoring and sharing results with other cities around the world.

C/Can 2025: City Cancer Challenge

Good Health and Well-being Partnership for the goals

Sustainable Cities and communities

Challenge Cities in 2020



Greater Petaling, Malaysia

- TOTAL POPULATION: 1.4 million
- POPULATION REACHED BY HEALTHCARE FACILITIES: Not currently available
- CANCER INCIDENCE (PER 100,000): 139.9
- CANCER MORTALITY (PER 100,000): 85
- PREMATURE CANCER RATE (PER 100,000): 67.1
- MOST COMMON CANCER SITES: MALE: Lung, liver, leukemia, prostate, nasopharynx
- MOST COMMON CANCER SITES: FEMALE: Breast, lung, colorectal, leukemia, liver

Primary City Cancer Challenge Partners: Patient Organisation National Cancer Society Malaysia Public Sector Tertiary Academic Institution: University of Malaya

Greater Petaling: Engaged Stakeholders

<h3>Federal Government</h3> 	<h3>Private Insurance Providers</h3> 	<h3>Clinical Institutions - Hospitals</h3> 	<h3>Medical Professional Associations</h3> 
<h3>State Government</h3> 	<h3>Non-governmental Organization & Civil Society</h3> 	<h3>Social Welfare NGO</h3> 	<h3>Religious NGO</h3> 

C/Can Model

PROCESS ORIENTED TIMELINE - SCHEDULED ACROSS TWO YEARS

Learn			Empower		Grow	
<h4>Due Diligence</h4> <ul style="list-style-type: none"> Determination of whether city is suitable for joining the challenge Assessment incorporates critical factors such as population, number of facilities, political buy-in and other factors 	<h4>Stakeholder Engagement</h4> <p>Convening of local leaders across sectors (government, CSOs, international agencies, bilateral and multilateral agencies, academia, research centres, healthcare facilities, professionals, professional societies, private sector)</p>	<h4>Needs Assessment</h4> <ul style="list-style-type: none"> The Convened City Executive Committee undertakes a comprehensive, city-wide, data-driven needs assessment Determines gaps and priorities 	<h4>Action Planning</h4> <p>Development of an activity plan based on the needs assessment, including identification of relevant partners and institutions at the city level</p>	<h4>Technical Analysis</h4> <ul style="list-style-type: none"> Identification of appropriate channels for technical assistance partnerships, collaboration both locally and internationally Engagement with City Health Financing Lab to assess one-off investments and/or longer-term financing solutions to support implementation of action plan 	<h4>Implementation</h4> <p>City Managers and City Executive Committee implement the action plan, alongside a robust monitoring, evaluation and learning framework</p>	<h4>City-to-City Sharing</h4> <ul style="list-style-type: none"> Data sets, case studies, best practices shared across global network of cities as well as to other cities within the same country Local progress leading to global impact
<h4>City Challenge Game Plan</h4>						
<h4>End-Game</h4> <ol style="list-style-type: none"> Increase accessibility to cancer care services in the challenge city Increase rate of early detection in the challenge city Increase survival rates of cancer patients in the challenge city 			<h4>Proposed Solution</h4> <p>A free, individual-based navigator application for challenge city-residents able to do the following:</p> <ol style="list-style-type: none"> Assess an individual's risk for cancer, prompt requirements for screening and also provide avenues for patient to get his/her screening done on a routine basis Connect different levels of clinical care providers, financiers (such as insurance providers and employers) and other stakeholders at patient level so that he/she can proceed to receive the care needed (such as screening, diagnosis, treatment, palliative care and others) 			



Opportunities for Patients Organizations

- Opportunity to gain a seat at the 'decision-making' table
- Opportunity for policy-shaping & agenda-setting
- Opportunity for advocacy
- Opportunity to groom/nurture Key Opinion Leaders
- Opportunity for multi-sectoral partnership
- Opportunity for project/programme funding
- Opportunity for gainful community-level sustainable change

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BACK

Mental Health Care As A Vital Part In The Holistic Care For Patients And Families With Rare Diseases

MENTAL HEALTH CARE AS A VITAL PART IN THE HOLISTIC CARE FOR PATIENTS AND FAMILIES WITH RARE DISEASES

Leading Author: MSc. Vesna Aleksovska, Licensed Psychologist, Gestalt Psychotherapist, Supervisor, Founder and General Manager of NEOCORTEX
Co-authors: M. Sc. dr. S. Jovana Malinovic, Founder and President of Association of citizens for rare diseases LIFE WITH CHALLENGES, Izola; Aleksandra Stojanovic, Psychologist in NEOCORTEX

LIFE WITH CHALLENGES has a successful helpline for over 5 years now. The free psychological support was implemented in 2019 and in 2020 it continues to grow as a network of psychologists and psychotherapists. Mental healthcare and psychological wellbeing are recognized as a vital part of the holistic care, which was until now lacking in the support of the patients with rare diseases in the Republic of North Macedonia. We focused not only on the patients but also on their immediate family members, who are also severely psychologically affected and experience severe psychological stress, trauma and sudden change in the family dynamics and every day functioning.

RARE DISEASE PATIENT

- Lack of medical diagnostic procedures and treatment
- Anxiety disorders
- Depression
- Chronic stress
- Social isolation
- Diagnostic mistakes
- Delays in diagnosis
- Family dysfunction and divorce

OUTCOMES:
 The implementation of free psychological support and treatment within the other services provided by the Association LIFE WITH CHALLENGES encompassed an important aspect which was identified as important need for these patients. Around 40 patients with their families received psychological support for 2019, and the number is constantly growing due to the recommendations and positive feedback.

The psychological care services were recognized and accepted as a service of paramount importance for prevention and treatment regarding mental health and overall wellbeing. The outcomes that we noticed in the patients are:

- Anxiety reduction
- Improvement in the mood and will
- Better stress resilience and coping mechanisms
- Better life activity and day organization
- Increased feeling of control over their condition
- Better quality of life and wellbeing
- Facing and accepting their illness
- Better socialization and openness in interpersonal relationships
- Improved family dynamics and reorganization
- A more personal feeling of self-worth
- Empowered patients and caregivers
- Decreased feeling of stigma and marginalization

CONTACT ME:
 Phone: +38970 70 54 46
 Email: info@lifewithchallenges.mk
 Web: https://lifewithchallenges.mk/en/

FUTURE STEPS:

- Psychotherapy group for support of family members of patients with rare diseases, especially parents of children with rare disease
- Other professional trainings and continual education for the team of psychologists who is working with the patients
- Group supervision for the team of psychologists
- Professional trainings for school psychologists, pedagogues and teachers, which will offer psycho-education for basic interventions, sensibilization, knowledge and tools for early detection of mental health disorders and deterioration in children with rare diseases and disabilities in the schools, and help for better integration
- We will continue with education of other psychologists and psychotherapists in our country and furthermore in the region where needed

Helpline for rare diseases:

- Over 400 phone calls and over 70 face to face meetings
- Communication through social media and e-mails
- 5 educational meetings organized and participated in over 10 conferences and meetings
- Exchange of information about clinical trials
- Connected over 20 families with rare diseases
- Creation of a web-site with information about rare diseases in Macedonian and Serbian language
- Cooperation on regional level and international level (EURODIS, IGA, IAPD, MDS, MPS, IPA...)
- Support to patients and families to establish their own patient organization (PAG SMA, MS)

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PAG Life with Challenges
 Vesna Aleksovska
 Engaging in Healthcare Transformation
 RARE DISEASE, PAN-RARE DISEASE
 Republic of North Macedonia



BACK

To Live with Haemophilia: Quality of life study - Sweden

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Swedish Hemophilia Society
Therese Backus
Engaging in Healthcare Transformation
RARE DISEASE, HEMOPHILIA
Sweden

Number of bleeds – underreported
Haemophilia, A or B, is an inherited bleeding disorder where a persons blood does not clot properly due to lack of insufficient levels of blood clotting factor. An accident, such as cutting your finger, or having a stroke, could therefore have very serious consequences. The treatment of hemophilia aims to minimize and avoid bleeds.

The biggest consequence for patients in their daily life is more or less regular internal bleeds that limit daily life. Our study shows that while haemophilia care is advanced in Sweden, there is an underreporting of bleeds. Bleeds that can have short term and long term consequences.

15% bleed more than once a month

44% of individuals with haemophilia A bleed several times per year

80% of the bleeds are triggered by accidents or physical activity

50% experience pain as a recurring problem

33% experience joint pain more than once a month

Lack of knowledge
There is a lack of knowledge in the healthcare system when it comes to haemophilia. Care is concentrated to three centers of expertise, however in the primary healthcare system and in emergency care there is still very little knowledge about haemophilia.

"Healthcare personnel must increase their knowledge about haemophilia. It is a matter of life and death"

To live with constant worry
Many with haemophilia report feeling limited by their worry. Their worry is often related to pain, and that treatment will be difficult in terms of finding a vein or injuring oneself. Many refrain from activities out of fear of injury. Worry is common in parents to children with haemophilia.

"He can never go anywhere and stay the night with his dad as his dad is worried about administering treatment"

63% with hemophilia A often feel worried as a consequence of the disease

Therese Backus
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China Illness Challenge Foundation (ICF)

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The Illness Challenge Foundation

Shuang Wang

Engaging in Healthcare Transformation

PAN-RARE DISEASE

China

病痛挑战基金会
ILLNESS CHALLENGE
FOUNDATION

生而非凡
BORN TO CHALLENGE

CHINA ILLNESS CHALLENGE FOUNDATION (ICF)

Rare diseases generally refer to diseases with low prevalence and few patients. There are nearly 8,000 different types of rare diseases, affecting tens of millions of people in China. It is indicated that this catalogue will be expanded continuously. The vast majority of rare diseases cannot be cured. Patients with rare diseases face enormous challenges in many aspects of their daily life, including medical care and rehabilitation, as well as social inclusion. Challenges are also faced in the aspects of diagnosis and medical treatment, often encountered misunderstanding and discrimination, and the serious lack of institutional protection.

The Illness Challenge Foundation (ICF) is the first public welfare foundation in Beijing focusing on rare diseases. Through community services, industry support, and social advocacy, ICF is devoted to solving pressing problems faced by the rare disease communities on one hand, while on the other hand promoting an equal social environment for the rare disease communities in a long run. Inspired by the "Ice Bucket Challenge", the Foundation was founded on 29th February 2016, the International Rare Disease Day.

ICF is committed to supporting the medical rehabilitation of rare disease patients, nurturing autonomous patient organizations, building platforms for multiple stakeholders, creating brand projects with strong public engagement, promoting institutional support for rare diseases, and solving pressing problems faced by the rare disease communities, including medical rehabilitation and social inclusion. By doing so, the ICF aims to create a supportive, righteous, and inclusive social environment with everyone's rights respected regardless of the disease one suffers from or the challenges one faces.

Vision: Create an equal and respectful social environment for the community challenged by illness.
Mission: By focusing on the development and empowerment of communities, through establishing platforms and cooperating with multiple resources and actors, to solve urgent matters faced by the rare disease community.
Slogan: Born to Challenge

Working Projects

- 1. Community Services**
Rare Disease Medical Support Program
- 2. Industry Support**
Rare Disease Empowerment and Collaboration Platform
Rare Disease Symposium on Collaboration and Communication
Policy Advocacy
- 3. Social Advocacy**
"People born to challenge" Short Documentary Series
"People born to challenge" Art to Voice Project
International Rare Disease Day Public Advocacy Program

Contact Us

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BACK

Health: An Asset and a Right That Needs to be Protected and Promoted



IN COLLABORAZIONE CON



LA SALUTE: UN BENE DA DIFENDERE, UN DIRITTO DA PROMUOVERE

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Salute Donna Onlus

Roberto Francesco Mazza

Engaging in Healthcare Transformation

ONCOLOGY, PAN-ONCOLOGY

Italy

A political and institutional advocacy project which was launched in 2014 by Salute Donna Onlus, and it's now supported by other 27 Patients' Associations, with the aim of contributing to the improvement of care and treatment of cancer and onco-haematological patients, which is usually characterized by delays and serious regional disparities.

GOAL

To create a continuous dialogue between:

- Patients' Associations
- Scientific Societies
- Doctors
- Pharmaceutical companies
- Institutions
- Legislative and executive powers

To

- Ensure better management and treatment of cancer and onco-haematological patients
- Promote greater equality of treatment in the various Italian regions
- Inform national and regional political representatives about Oncology in general and the main problems surrounding it

CANCER IN ITALY

- 1000 new cases of cancer in Italy every day
- over 3 million people today live with this disease in our country

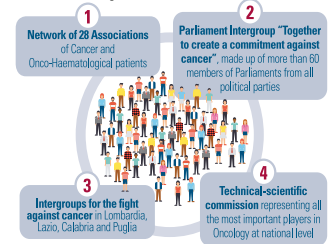
Advances in research are improving disease control, but patients are demanding greater financial commitment from the Italian health system.

Patients receive different health benefits due to regional healthcare autonomy.

Patients' Associations request that the issue of cancer becomes a priority in political agendas, while still taking into account the sustainability of the National Health System.

THE NATIONAL PLATFORM OF STAKEHOLDERS IN ONCOLOGY

To create an effective impact on the Institutions and to improve patient care and treatment at national level, a permanent advisory and operational platform has been created consisting of:



WHAT WE WORK ON

- National Cancer Plan (PON)
- Oncology networks
- Fund for innovative cancer drugs
- Diagnostic Therapeutic Care Pathways (PDTA)
- Molecular diagnostics
- Quick access to drugs
- Care center and services (CAS)
- Primary prevention
- Correct lifestyle

DOCUMENTS OF THE PROJECTS

With the help of all the people involved in the initiative the following were made:

- A Policy Paper which analyzes what exists at the moment at regulatory level in Italy in order to have better management of patients and it indicates the areas where intervention is a priority.
- An Agreement signed by all the players involved in the project that illustrates the main topics on which the Patients' Associations want to work on at national and regional level in the current Legislature.

ACHIEVEMENTS TILL DATE



AT NATIONAL LEVEL

- Five motions which incorporated the project's Legislative Agreement were approved by the House of Parliament and the Senate. These highlighted the Government's commitment towards: the implementation of the National Cancer Plan; the activation of Regional Oncology Networks; equal access to innovative cancer drugs; adoption of correct lifestyle.
- To implement a 500-million-euro fund for innovative cancer drugs.

AT REGIONAL LEVEL



Lombardia

- Approval of the motion on extending the eligibility criteria for ticket exemption for women with BRCA1 and BRCA2 genetic mutation.
- Approval of the motion for the creation of a Diagnostic Therapeutic Care Pathway for metastatic breast cancer.

Lazio

- Inclusion of a greater commitment to better take care of cancer patients in

the economic and financial planning document.

Puglia

- Carrying out of a survey on the cancer and onco-haematological situation in Puglia with the involvement of oncologists, haematologists and the local Patients' Associations.

Calabria

- Approval of a motion for the creation of the Regional Oncology Network.

CONCLUSIONS

The activity of monitoring patients' needs in Italy will continue as well as the advocacy activities at national and regional level in order to keep contributing to the improvement of the conditions of patients throughout the country.

TO KNOW MORE

www.salutebeneadifendere.it
www.saluteoncoldas.it

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BACK

Together Against Cancer



(TOGETHER AGAINST CANCER)

Created in 2017 we are the biggest and more inclusive national cancer movement. We are more than 60 NGOs all over Mexico, united in the creation of a common cancer public agenda. We want to transform cancer patients needs into public policy programs for the prevention, early diagnose, access to treatment, rehabilitation and palliative care in our country.



What is the current situation we are facing?

- Third cause of death
- One in three people will have a positive diagnosis of cancer by 2025
- Mexico does not have a National Cancer Control Plan
- 45% of the treatment expenses are paid by patients and families
- 70% of the diagnoses are made at latest stages (III-IV)

How are we going to change it?

Our proposals for a Cancer Control Program in Mexico, centralized on the patient:



- Primary prevention
- Screening and early detection
- Access to the best cancer treatment in a timely manner
- Palliative Care
- Rehabilitation

Always keeping in mind

Key priorities for Juntos Contra el Cáncer (Manifiesto)



1. Cancer should be considered a priority in the public agenda as both in the National Development Plan and the Health National Program
2. Patients care must be included in the nation's health policy
3. Universal access to prevention, prevention, early diagnosis, personalized treatment, palliative care and rehabilitation for cancer patients must be guaranteed without discrimination based on gender, age, social conditions, ethnicity, origin, socioeconomic status or any type of risk protection
4. Public health services must serve in a timely and equally available way to ensure coverage for people with cancer, according to the epidemiological situation of the Mexican population
5. Strengthening training and continuing education of cancer-related health professionals in matters of techniques, best practices and evidence-based, according to the needs of the patient, when necessary
6. Development, innovation and regulatory issues be viable for the benefit of oncological patients

Skills, experience and position to effectively advocate for cancer control



The organizations of Juntos Contra el Cáncer from all around the country have years of experience on implementing advocacy strategies, collaborating with health professionals, legislators and authorities

We have partner organizations to join forces and collaborate with Juntos Contra el Cáncer on three perspectives: NCD's, democracy and transparency and Multilateralism (UN, WHO/PAHO American Region and the UICC)

Our main achievements are:



- Organization for the first time of more than 60 organizations across the country in one movement
- We are considered as the main valid voice of the oncological patients' needs with health authorities
- We have presence in international congresses such as the World Cancer Leader Summits and National Assemble of UN

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Asociación Mexicana de Lucha Contra el Cáncer & Sintra, Adela Ayensa

Mayra Galindo & Adela Ayensa
Engaging in Healthcare Transformation
ONCOLOGY, PAN-ONCOLOGY
Mexico



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BACK

In The Rhythm Of The Human Brain

David Krivec, Spominčica Alzheimer Slovenija, Ljubljana, Slovenija
david.krivec@spomincica.si | www.spomincica.si

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Spominčica – Alzheimer Slovenia
Engaging in Healthcare Transformation
NEUROSCIENCE, PAN-NEUROSCIENCE
Slovenia

5 NEUROLOGICAL DISEASES
DEMENTIA | PARKINSON'S DISEASE MULTIPLE SCLEROSIS | HUNTINGTON'S DISEASE SPINAL MUSCULAR ATROPHY

6 PATIENT ORGANIZATIONS



1 CHALLENGE

IN THE RHYTHM OF HUMAN BRAIN

V RITMU ČLOVEŠKIH MOŽGANOV

EDUCATION, AWARENESS RAISING, AND POLICY SHAPING EVENT



Clinical experts presenting each disease, advances in treatment, and challenges

Panel discussion about the needs of the patients and their families with HCPs, patients, caregivers and policymakers



**Mr. Marjan Šarec,
Prime Minister,
General Patron**

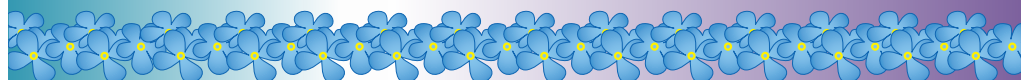
**Ms. Aiga Rurane,
WHO Regional
Office Slovenia**



**Where was I?
Theatre play
about dementia**



More than 200 participants: patients, caregivers, professionals, policymakers



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BACK

Be MUT-ual Days - Oncogene driven Cancers: The New Paradigm

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WALCE
Stefania Vallone
Engaging in Healthcare Transformation
ONCOLOGY, LUNG CANCER
Italy



Be MUT-ual Days
Oncogene driven Cancers: the new paradigm
25 – 26 November 2019 - Rome
WALCE (Women Against Lung Cancer in Europe) Onlus

BACKGROUND

The number of lung cancer patients is increasing. Today in Italy there are almost 107 thousand (106,915), while in 2010 there were 82,795: in 10 years the increase was 29%. This is a very important result in aggressive and difficult cancer to treat. To give voice to long-term survivors, an event has been held in Rome in November, entitled "Be MUT-ual Days", the first in the field of thoracic oncology, aimed at people with non-small cell lung cancer characterized by molecular alterations (oncogene addicted) and their caregivers. For two days, 80 patients from different Italian cancer centers, 60 caregivers and 30 doctors discussed the critical issues and new needs generated by innovative treatments and the possible actions and solutions to be adopted to fill the gaps still existing. The event was organized by WALCE (Women Against Lung Cancer in Europe), a non-profit association, founded in 2006 in Italy, with the primary objective of increasing women's awareness of the increasing incidence and mortality of cancer of the lung in the female gender and to inform, educate and support patients affected by this disease during their journey.

PHOTO GALLERY



"Be MUT-ual Days" - Photos of the event, 25 and 26 November 2019



"Be MUT-ual Days" photo of the round table ISS (M. Biffoni), AIOM (G. Beretta), SIAPEC (A. Sapino), WALCE (S. Vallone), CittadinanzAttiva (A. Gaudioso), FAVO (E. Iannelli), Insieme contro il Cancro (F. Cognetti), Salute Donna (A. Mancuso), Ricerca e Innovazione in Sanità (C. Leonardi)

METHODS

- The event was organized in Rome, with the patronage of other organizations: WALCE Puglia, FAVO, Women's Health and Men's Health, Active Citizenship and Together against Cancer and it was a multisponsorship initiative.
- The first day "Be MUT-ual Days" was opened by "Apolide", a short film, which this year won the 3rd prize of the competition offered by AIOM (Italian Association of Medical Oncology) and AIOM Foundation entitled "oncology and cinema"
- This was followed by a lecture presented by Prof. Benjamin Besse, an international KOL, who focused his attention on the state of the art of lung cancer treatments and future prospects.
- Finally Merel Hennink, a Dutch patient who shared her experience as a patient with NSCLC ROS1 and as advocate very active nationally and internationally.
- On the second day, patients and caregivers had a dedicated space to discuss, separately and guided by two moderators, about different issues related to the management of their disease and the possible actions necessary to partially solve the gaps they daily face with. The results collected during the two workshops were communicated and shared during the round table with other stakeholders.

OBJECTIVES

- People living with lung cancer, today and especially in some countries, including Italy, still struggle to contact patient Associations and be active protagonists in their disease and treatment path.
 - Thanks to new therapeutic approaches, that in the last 10-15 years have significantly changed the scenario of lung cancer, today the number of people living longer and with a good quality of life has grown and many patients begin to acquire more skills and to have a greater interest in everything related to one's health and therefore to be more involved in decisions concerning their illness.
 - In particular, people who receive a diagnosis of oncogene addicted NSCLC, often, since younger and with a better quality of life have the perception of not having enough in common with larger groups, but rather having more specific clinical needs, education and emotional, related to their disease.
- The educational event was dedicated to this setting of patients in order to:
- Better identify their specific needs
 - Offer two days for improving their knowledge and education about molecular tests and innovative treatments
 - Encourage the creation of a network, so that they can share their experiences and common needs
 - Support the group through the creation of specific educational resources
 - Improve the quality of life of these patients

RESULTS

- During the event, different needs related to the patient's care path and some proposals to facilitate the solution of these problems emerged from the two groups, patients and caregivers:
- NEEDS
 1. Patient / caregiver and system information
Receiving more information about the disease, the clinical trials and experimental drugs. Being supported in the communication to children.
 2. Improving the perception of teamwork and multidisciplinary
 3. Providing more information about patient and caregiver rights: protection of employees and self-employed workers, economic and welfare protection
 - PROPOSALS
 1. Information conveyed by official channels (dissemination of website addresses, guidelines, information brochures)
 2. Creation of a community for sharing information and strategies for managing disease and the side effects of treatments
 3. Active contribution in the development of research protocols and national cancer guidelines

CONTACTS
<http://www.womenagainstlungcancer.eu/>
stefania.vallone@womenagainstlungcancer.eu



BACK

The 'AHESC comes to you' Project



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Associação Dos Hemofílicos Do Estado De Santa Catarina

Maisa Vieira
Engaging in Healthcare Transformation
RARE DISEASE, HEMOPHILIA
Brazil

INTRODUCTION AND OBJECTIVES

The Association of Hemophiliacs of the State of Santa Catarina (AHESC) is a charitable association which aims at improving the quality of life of people with hemophilia, von Willebrand and other coagulopathies and their families throughout the state of Santa Catarina, Brazil. AHESC offers its members and their families free temporary social care, food, physiotherapy, hydrotherapy and legal advice. The AHESC comes to you project seeks to address one of the main complaints reported by members, i.e. lack of information on the part of both health care professionals and hemophiliacs and their families.

This project aims...

- ADDRESSING THE LACK OF INFORMATION ON HEMOPHILIA
- ENABLING ACCESS TO TREATMENT
- INCREASING TREATMENT ADHERENCE

MATERIALS AND METHODS

OBJECTIVES	ACTIVITIES	RESULTS
PROMOTING EVENTS	NOTIFYING MEMBERS OF TALKS BY USING E-MAIL, WEBSITE, FACEBOOK AND PHONE CALLS.	LOCAL AND REGIONAL ATTENDANCE OF HEMOPHILIACS, THEIR FAMILIES AND HEALTH CARE PROFESSIONALS
SHARING KNOWLEDGE AND EXPERIENCES AND PROMOTING SOCIAL INTEGRATION	VISITS TO THE BLOOD CENTERS OF SANTA CATARINA LOCATED IN THE CITIES OF CRICIUMA, JOACABA, LAGES AND CHAPECÓ	EMPOWERMENT OF HEMOPHILIA PATIENTS AND THEIR FAMILIES IN SEARCH OF TREATMENT AND OF THEIR RIGHTS AS WELL AS BETTER CARE, ADEQUATE PROCEDURES AND SAFETY ISSUES FOR HEMOPHILIACS
PROMOTING SOCIAL INTERACTION AMONG HEMOPHILIACS, HEALTH CARE PROFESSIONALS AND AHESC. PROVIDING A SPACE FOR SOCIAL INTERACTION, THEREBY HELPING TO CREATE A NETWORK OF SUPPORT AND GUIDANCE	TALKS GIVEN BY HEALTH CARE PROFESSIONALS: HEMATOLOGISTS, SOCIAL WORKERS, NURSES, PSYCHOLOGISTS AND PHYSIOTHERAPISTS. COFFEE BREAK	SOCIALIZATION AND SHARING OF EXPERIENCES

RESULTS

This project has enabled health and education professionals as well as hemophiliacs and their families to have more confidence and information on hemophilia. The relationship between the agents involved has been strengthened and, as a result, treatment adherence and motivation to seek adequate treatment have improved.

CONCLUSION

Health care professionals had the opportunity of meeting in person many users they had previously contacted via phone calls, text messages or e-mail only. Users, in turn, had the chance to speak about their personal experience with hemophilia and their difficulties and ask questions. Testimonials were given based on which relevant measures were taken. Major concerns were: difficulty going to the blood centers caused by problems related to transportation provided by the patients' city administration; coagulation factor availability; coagulation factor transport difficulty.



FOR MORE INFORMATION

AHESC
ahesc@ahesc.org.br



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Cancer Survivors Association



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Kanser Savaşçıları

Nagehan Uzuner

Engaging in Healthcare Transformation
ONCOLOGY, PAN-ONCOLOGY
Turkey

Kanser Savaşçıları Derneği/Cancer Survivors Association

Cancer Survivors Association (CSA) is a civil initiative that researches, learns and shares all kinds of information that may be needed in the diagnosis of cancer and cancer treatment processes from the correct and scientific sources. After serving as a civil initiative in the field of activity for three years, Cancer Survivors became an Association in 2015 and gained a corporate identity. CSA deals with all types of cancer rather than specifically dealing with a single type of cancer. The Association transfers the best knowledge and experience of the important scientists to patients and their relatives. We make bridge between the cancer survivors who have experienced or are in the process of diagnosis and treatment to share their experiences with each other and to guide others. We carry out projects on education, awareness and psychological support all around in Turkey. We also proudly represent our country and our works in the International Patient Associations platforms.

CSA offers professional support to cancer patients and their relatives in public hospitals, such as psychological counseling, oral and dental health, and nutritional support and also establishes play rooms for pediatric oncology services. Being aware of the economic, social and psychological difficulties of cancer, the main task of The Association is to produce solutions for different issues that may be needed during and after the cancer.

- ✓ With “Saçım Saçım Olsun (Let’s my hair be yours) Project” we use the donated hair by volunteers to prepare free wigs for cancer patients who are in need of wigs due to their cancer treatments.
- ✓ CSA organizes “look good, feel good” workshops for adult patients and cancer awareness seminars in the early diagnosis and wellness issues.
- ✓ CSA has plans to build a guesthouse near Kocaeli University Research and Application Hospital.
- ✓ CSA created “Onkobis Project (Oncobike Project)” for children between 2-6 years who are diagnosed with cancer at an early age. The environments where the children can meet their peers, play games and socialize during their treatment are not easily provided due to the risk of infection. For the very reason of these we designed serum suspension bikes, which we call “Onkobis (Oncobike)” to help these children to continue their movements throughout their treatment in hospital hallways and reduce their attachment to the bed. 141 onkobikes are given to the children’s oncology and hematology departments of 32 hospitals in Turkey.
- ✓ CSA is one of the leading founders of The Cancer and Patient Rights Platform (CPRP) in Turkey. This Platform is established to inform cancer patients, relatives of patients, health-related NGOs and healthcare workers and to create public awareness about the patient rights. CPRP, which is open to all individuals and entities aiming to improve the right to health and patient rights, works to fight against access to new drugs and treatments. CPRP produces books, brochures and videos convey information (www.hastahakki.org)

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Delegate: Nagehan UZUNER

Mrs. Uzuner holds BA in Public Relations and Promotion from Ege University and MA in Marketing Communications from Istanbul Bilgi University. She worked as Marketing Communications Responsible at KüçükÇiftlik Park. Later she was transferred to Assicurazioni Generali as Head of Italian Desk & Communication and Mrs. Uzuner switched her company and started to work for Legrand as Corporate Communications Manager. After surviving one of a rare cancer disease she became a scholar at the same time as her business life in 2017. Thus she started to do Ph.D. in Communication at Istanbul Bilgi University. Currently she is a Ph.D. Candidate and her doctoral thesis and research area focus on Health Communications. She is Volunteer and Board Member of Kanser Savaşçıları Derneği (Cancer Survivors Association) for years. She is responsible for the events and the communication needs of The Association. Mrs. Uzuner is a proud member of Koç University Ethics Committees such as; Ethics Committee for Clinical Research, Ethics Committee for Biomedical Sciences and Ethics Committee for Social Sciences.

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Ovarian Cancer Australia

Jane Hill

Engaging in Healthcare Transformation
NOT DISEASE AREA SPECIFIC
Australia

THE CANBERRA HEALTH SUMMIT AND THE ESTABLISHMENT OF

THE AUSTRALIAN PATIENT ADVOCACY ALLIANCE

The Challenge

While there are many highly effective disease-specific patient advocacy groups in Australia, a united voice is needed to advocate for broad and meaningful healthcare system change, and patient involvement in policy decisions.

Objectives

1. Co-create meaningful policy solutions for patients across four key themes: Evidence, Innovation, Productivity & Data
2. Effect positive health system change by engaging with policymakers



Wow! What did we just do? It's a recognition that you can achieve so much by working together.

COMMITTEE MEMBER



STEERING COMMITTEE MEMBERS

Jane Hill (Co-Chair), CEO Ovarian Cancer Australia;
Deidre Mackechnie (Co-Chair), CEO MS Australia;
Nettie Burke, CEO Cystic Fibrosis Australia;
Sharon Caris, Executive Director Haemophilia Foundation Australia;
Sharon Winton, CEO Lymphoma Australia



Above: The Hon Chris Bowen MP, Shadow Minister for Health, speaking at the Canberra Health Summit

Right: 2019 Canberra Health Summit Consensus Statement

Solution & Approach

- Two-day multi-stakeholder Summit at Parliament House in Canberra, sponsored and organised by Roche.
- 22 patient organisations came together to discuss policy and agree on a common advocacy agenda. Together they represented 15 million patients (more than 60% of Australians) - a reminder of the power of a united consumer voice.
- Agenda and speakers determined by an independent steering committee of patient group CEOs from a range of disease areas.
- The Steering Committee held important pre-meetings with:
 - Key policymakers including representatives from the Prime Minister's office, the Minister for Health's office and the Department of Health, to seek commitment on policy change across the Summit's themes; and
 - Each Summit delegate, to seek input and encourage participation.



Top: 2019 Canberra Health Summit Steering Committee
Above: Australian Patient Advocacy Alliance members

Outcomes

Delegates agreed on five key policies outlined in a Consensus Statement that was presented to policymakers. The five priorities were:

1. Codify the principle of consumer co-design in health policy-making in legislation or regulation
2. Establish a national database for PREM/PROMs for all diseases
3. Undertake a review of current measures/indicators/benchmarks used in National Health Agreements, led by the Productivity Commission
4. Develop a white paper on the deployment of Artificial Intelligence to drive better health outcomes
5. Review the Health Technology Assessment process to ensure it is fit for purpose/determine role of real-world evidence

Summit delegates agreed to form the **Australian Patient Advocacy Alliance – the first group of its kind in Australia**. The launch of APAA was announced to media in October 2019.

The Minister for Health invited the Alliance to represent the patient voice on two key Government advisory bodies - the **National Preventative Health Strategy** and **National Medicines Policy Review Working Group**.



Great initiative and taking place at exactly the right time.

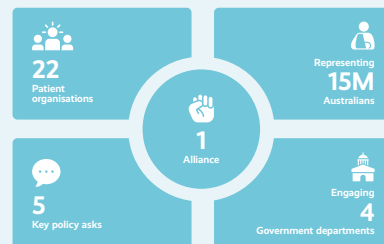
THE HON GREG HUNT MP, MINISTER FOR HEALTH



The Hon Greg Hunt MP, Minister for Health, speaking at the Canberra Health Summit

Key Learnings & Takeaways

- The power of a united patient voice
- Leave your disease at the door!
- Summit and establishment of APAA highly valued by individual patient groups
- Secure funding for a Summit and an Alliance is critical, but patient groups must own the agenda
- Pre-briefing politicians and securing their buy-in is key to constructive engagement
- Collaboration is king – with health and economic policy experts, policymakers, individual patient groups and industry – with the engagement leading to a commitment from the Government to co-create policy solutions with the APAA



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MDbaby care center
Gongsheng CHEN
Engaging in Healthcare Transformation
RARE DISEASE, DUCHENNE MUSCLE
DYSTROPHY
China

MDbaby Care Centre, China

Ladies & Gentlemen, Come on. We need your attention

Come on. We welcome all Patient Organizations from the world to join us to expand our social influence globally.

We also welcome all global Pharmaceutical Research Institutions and Companies to China.

Share the Opportunities in China

With country's largest market

China is the world's most populous country. With the largest number of patients it has become the largest market of potential medical demand. In China, there are about 60000-100000 DMD patients.

With the strongest demand

China is the most remarkable developing country in the world and the world's second largest economy. The Chinese have the strongest purchasing power for medical products. We are always looking for the right medicine/treatment to ease the pain of DMD patients, whatever it takes.

With the most streamlined network

China has the largest number of medical institutions in the world and the world's best medical equipment, resources and sufficient personnel in the 15 first-tier cities. It also has a large number of international clinical conversion companies to support the implementation of the trial project.

Share the Community dividend

To manage the largest communities

We are parents of DMD patients, and no one can love children than their parents. In China, there have been more than 5 patient organizations and more than 20 patient communities established through the Internet. Manage and carry out self-help and mutual assistance, psychological care, medical guidance, disease science and other services. Patient organizations have more communities and patient data than hospitals.

To serve as the bridge and platform

In China, the patient organizations are public welfare institutions (NGO). For pharmaceutical companies, patient organizations are clients. For the government, patient organizations need special help and support. For medical research parties, they are the original source of research samples. Patient organizations promote stakeholders and promote policy change, assist in scientific research, and development and progress. We open our doors and work with leading pharmaceutical companies around the world.

Innovation & invention

Rare disease patients need support from the country, scientific research and society, but patient organizations cannot rely entirely on this approach. Pengpeng Technology Co., Ltd is an innovative company funded by patients' parents. At present, intelligent breathing training and rehabilitation equipment based on AI and big data have been successfully developed. In the future, more medical products will be developed based on patients' needs.

Actions and achievements

- In 2016, we learned that United States PTC Pharmaceutical Company needed to carry out more clinical trials on patients in the process of DMD drug development. Subsequently, we actively contacted PTC in the United States and coordinated with the national drug regulatory agency and medical institutions. In 2017, our patient organization successfully held a communication meeting with PTC Company, which finally led to the launch of clinical trials in many places of China.
- In 2018, MDbaby Care Center designed a one-year program to support the rehabilitation of DMD patients, which was eventually selected and fully funded by the government.
- In May 2018, members of the DMD Organization from Zhejiang province, China visited the United States National Children's Hospital and held independent talks with Pat Furlong, the founder of PPMD. This negotiation established the cooperation between Chinese and American patient organizations to achieve better communication.
- In October 2018, DMD from Zhejiang province, China, together with Sanofi, organized a rich and interesting communication activity for patients with DMD rare disease in China, hoping to improve patients' confidence, self-care and social skills in this way.

Of course! Since 2018, we have been invited to attend CEPPD held by Roche China. We have done much more and we are looking forward to creating more with your joining.

About MDbaby

MDbaby originated from the DMD patient community. In 2016, it was officially registered as a government recognized legitimate organization. MDbaby speaks, advocates and appeals on behalf of patients. We carry out various forms of science popularization activities to improve the social awareness of rare diseases. We work with medical institutions to manage patients and accelerate drug clinical research. In the past four years, we have served more than 3000 patients.

感谢罗氏。

MDbaby Care Center From Chinese parents & patients Organization of DMD Rare Disease
WWW.MDBABY.ORG E-mail: info@mdbaby.org Tel: +8615889608182
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Pembe İzler

Ayşem Baykara

Engaging in Healthcare Transformation
ONCOLOGY, OVARIAN CANCER

Turkey

Pink Route

OUR ROUTE IS PINK, OUR FUTURE IS SAFE!
PEMBE İZLER WOMEN'S CANCER SOCIETY

Pink Route project has been developed based on the low awareness about the gynecological cancers in Turkey. With this project, we emphasise the importance of early diagnosis and give support to treatments of women.

OUR AIM

To raise awareness about gynecological cancers.

OUR GOAL

To provide free gynecological cancer screening for 10,000 women

HOW DID WE PROCEED?

**We took our healthcare experts with us.
We also cooperated with local healthcare professionals.**

WHEN WE STARTED?

May, 2018

WHERE DID WE GO?

İSTANBUL, BODRUM, BURSA, MARDİN

WHERE WE PLANNING TO GO?

**DIYARBAKIR, ANKARA, KAYSERİ, ANTAKYA,
İZMİR GAZİANTEP, İSTANBUL, ADANA**



- So far, we have met more than 1.850 women face to face.
- 739 of them examined for free
- 33 of them were diagnosed with cancer,
- 77 gynecological cancer operations and interventional procedures were performed free of charge and
- 12 women underwent protective surgery at no cost.
- We reached out to vast audience with our news in the press and social media.

Pembe İzler Women's Cancer Society; (founded in 2014)

Pembe İzler Women's Cancer Society aims to raise public awareness about all types of women's cancer particularly for breast cancer and to provide support in the diagnosis and treatment of the patients with financial inadequacy. In other words, it aims to give patients and patient relatives a helping hand in this quite important challenging situation. It aims to raise awareness by telling the truth and practicing accordingly. In order to make this widespread as possible, it prepares various qualified and comprehensive projects.

The society is the most prominent supporter of women fighting with women's cancers during and after the treatment and it aims to help these afflicted women to maintain their lives as strong women who are not afraid of the disease and its results.

This poster complies with the laws/regulations of Turkey
Contact : Ayşem Baykara (phone: +90 532 4337749
e-mail: aceylanb@gmail.com)



<https://kadinkanserleridernegi.org/>

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BACK

The Cancer Patient Forum Vol. 2 "Cancer Policy"

Advocating for the development of Cancer Policy in 🇺🇦 Ukraine

PRESENTER: NGO Soul Sisters, Anna Uzlova

WHO WE ARE: Soul Sisters, Cancel/R, Kvant – three NGOs that joined forces to empower the capacity to represent patients' rights, to advocate for positive changes more effectively and to do more for the patients with oncologic nosologies

The Cancer Patient Forum VOL. 2 "Cancer Policy"

The platform which we organised and conducted on 04 February 2020

WHY IT WAS NECESSARY

- The government puts 'low priority' label on the cancer patients' problems
- Ukraine lacks effective diagnostic mechanisms for early detection of disease
- PHC approach is totally absent
- Proper palliative care doesn't exist

THE IMMEDIATE OUTPUTS AND OUTCOMES OF THE FORUM ARE

- We managed to mobilise the majority of the stakeholders;
- We succeeded in raising the awareness among the Ukrainian population on cancer and the situation with its treatment in the country;
- We bravely faced the challenge to shift the focus from the problems with the access to the treatment towards the crucial necessity to develop the global strategy for Ukraine in the regard of cancer;
- We kindly invited all the stakeholders (patients, HCPs, government representatives) for the multilateral discussion of the necessity to jointly develop the national plan on fighting cancer (which is currently non-existent in Ukraine)

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Soul Sisters
Anna Uzlova
Engaging in Healthcare Transformation
ONCOLOGY, PAN-ONCOLOGY
Ukraine

THAT IS HOW IT WAS



Our team



NGOs and patients



More photos



Deputy Minister
Ministry of Health of Ukraine



HCPs



Celebrity cancer survivors



Video



Panel discussion with stakeholders



Mass media



Anna Uzlova

THAT IS HOW IT WILL BE

OUR SHORTERM GOALS

- To ensure the inclusion of a wider range of patient representatives into the development of Cancer Policy in Ukraine;
- To be able to exert a positive influence over the appropriate allocation of budget funds to the procurement of effective and the most up-to-date treatment

OUR LONGTERM GOALS

- To contribute efficiently to the ensuring the extension of the access of Ukrainian patients to the most effective treatment according to their personal needs and specificities (PHC)

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BACK

Eliminating Disparities in Precision Medicine

Through a Patient-Provider Intervention

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LUNGeVity Foundation

Andrea Ferris

Engaging in Healthcare Transformation

ONCOLOGY, LUNG CANCER

USA



BACK

Progetto pilota di screening per la SMA



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Famiglie SMA Onlus

Anita Pallara

Engaging in Healthcare Transformation

RARE DISEASE, SPINAL MUSCULAR ATROPHY

Italy

Progetto pilota di screening per la SMA

Authors

Anita Pallara, Digital Strategist FamiglieSMA Onlus

Daniela Lauro, Presidente FamiglieSMA Onlus

Francesco Danilo Tiziano, Professore associato, Istituto di Medicina Genomica Università Cattolica del Sacro Cuore di Roma

1

What is screening?

All newborns are tested by law, in Italy, to allow early identification of several genetic and hereditary disorders

2

How and when is the screening performed?

Between 48 and 72 hours from delivery, and before the newborn leaves the hospital, a drop of blood is taken. Presently only in the Italian region Lazio, through the same blood sample it is also possible to detect SMA.

3

What is SMA?

SMA (Spinal Muscular Atrophy) is a rare genetic disease that affects voluntary muscles. Daily activities such as crawling, walking, controlling neck and head position and movements, even swallowing are difficult activities which become impossible at a later stage of the disease. 1 baby in 6,000 is born affected by SMA.

4

Why the pilot project was initiated in Lazio region?

The first therapy for SMA is finally available, and this treatment option showed excellent results if started as early as possible. Unfortunately so far the disease is not included in the neonatal screening required by law.

5

How can parents to join the project?

Informed consent must be signed. Thanks to participation, the genetic test for SMA can soon be offered to all children born in Italy

6

Results to date

- ✓ 15,008 infants tested as of 25 February 2020.
- ✓ 0.4% of parents "doesn't want to know the results" (61/15,004)
- ✓ Around 600 samples tested per week
- ✓ Birth points: 32 participating centres out of 33



BACK

Welfare Program 2016 - 2019: Advocating for the rights of people with MS in Italy

Italian Multiple Sclerosis Society (AISM)

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AISM - Associazione Italiana Sclerosi Multipla

Alessia Villani

Engaging in Healthcare Transformation
NEUROSCIENCE, MULTIPLE SCLEROSIS
Italy

THE PROJECT

The objective of the project was to develop the advocacy skills of MS Society volunteers across Italy.

The priorities set out by the MS Agenda 2020, evidence reported in the MS Barometer and an assessment of the regional political context demands a strong advocacy strategy articulated through concrete action.

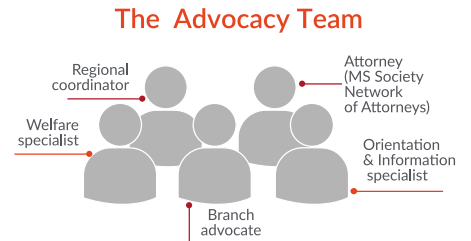
In order to effectively advocate for the rights of people with MS, it is essential to develop grassroots advocacy teams that bring the rights of those living with MS to the forefront of political agendas in every part of the country.

Advocacy teams are supported by legal consultants in the various Italian regions, in order to provide a legal agenda with a focus on protecting the rights of individuals with MS against discrimination.



TARGET

The project involves MS Society volunteers who have roles related to monitoring the political and regulatory situation on a local and regional level, as well as volunteers who are responsible for providing orientation and information to people with MS locally.



THE PROCESS

The Italian MS Society is committed to training volunteers to become advocates for the rights of everyone living with MS.

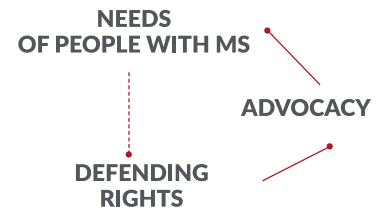
In 2018-2019, the MS Society focused on specific goals:

- Skill building
- Implementation of tools for assessing and comparing different political contexts
- Monitoring the implementation of regional advocacy plans
- Extending the network of legal professionals working across the country (MS Society Network of Attorneys) and providing them with education and information on MS-related issues.

Defending the rights of people with MS begins with understanding needs, expectations and individual circumstances. This is achieved through a dialogue between the Advocacy Team and people with MS facing discrimination. Volunteers trained in identifying discrimination and legal professionals with an understanding of MS, working together on a grassroots level, provide people with MS in critical situations of discrimination the support they require for defending their rights. The MS Society, through the Advocacy Team, helps people with MS defend their rights in every context of daily life.

This approach, combined with continual monitoring of the political landscape, increases the MS Society's potential for having an impact on the lives of people with MS.

2016-2019
30 volunteers 15 attorneys
became part of the regional Advocacy Team



un mondo libero dalla SM

AISM. INSIEME, UNA CONQUISTA DOPO L'ALTRA

alessia.villani@aism.it

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The project was supported by an unrestricted grant from Roche



BACK

Patient Involvement Decision Making: Chinese Practice on Childhood Cancer Comprehensive Control

Patient Involvement in Decision Making: Chinese Practice on Childhood Cancer Comprehensive Control



北京新阳光慈善基金会
New Sunshine Charity Foundation

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New Sunshine Charity Foundation

Songxin Zhang

Engaging in Healthcare Transformation
ONCOLOGY, PEDIATRIC CANCER
China

Abstract

As a patient organization, New Sunshine Charity Foundation, together with other charities and academic organizations, launched a comprehensive cancer control program for children in China, including charitable supplement medical reimbursement, health technology assessment and policy advocating, physician supporting and medical social work. Especially, we are working on patient involvement in HTA, RWE and PRD. Two drugs we assessed in 2018 were included in the drug list of medical insurance, which will save over 33 million US dollars a year for patients all over China. We also empower patients to work together to improve the accessibility and quality of health care.

Background

More than 42% of poverty in China is caused by illness. With the progress of poverty alleviation, this proportion is getting larger and larger. General Secretary Xi pointed out that healthy poverty alleviation is the hardest bone in poverty alleviation. In order to explore a regular solution to the problem of poverty caused by illness, New Sunshine Charity Foundation, together with three non-profit organizations and four academic institutions, jointly launched a social innovation social experiment—Associated Love Program. The vision of this program is to unite love to make poverty from illness disappear from modern China.

What we do

Associated Love Program was started in 2017, starting with childhood leukemia, and started the first regional trial in Heyuan City, Guangdong Province of China. In 2019, the first provincial pilot of Associated Love Program was officially launched in Qinghai Province. In the future, the Associated Love Program will be extended to more regions and diseases.

Associated Love Program has formed a four-in-one working model:

- (a) Established the "Associated Love - Charitable Medical Insurance Supplementary Fund" to increase the actual reimbursement rate of treatment of childhood leukemia to 90%.
- (b) Established "Associated Love - Medical and Health Technology Assessment Center" to evaluate widely used new drugs, good drugs, and expensive drugs in accordance with internationally accepted technical methods, to guide the use of charitable funds, and make policy recommendations to the national medical insurance department.
- (c) Established "Associated Love - Clinical Excellence Center" to support medical students' study and physicians' training, in order to improve the diagnosis and treatment capabilities in less developed areas to improve the rehabilitation of patients.
- (d) Established "Associated Love - Oncology Social Work Center", using professional methods of social work to help patients solve psychological and social problems.

Results and impact

In 2018, Associated Love - Medical and Health Technology Assessment Center evaluated two commonly used drugs for treating childhood leukemia—Fag-pegaspargase and imatinib (indications for the treatment of Philadelphia chromosome-positive acute lymphoblastic leukemia). The review was conducted based on the evaluation report, and policy recommendations were submitted to the national medical insurance department. With the efforts of many parties, Pegaspargase was included in the national medical insurance drug list in 2018, which will save 30 million US dollars for patients nationwide each year. Imatinib's indications for the treatment of Philadelphia chromosome-positive acute lymphoblastic leukemia are also included in the medical insurance list in 2018, which will also save patients about 3 million US dollars each year.

As to the Clinical Excellence Center, we supported a doctor of Heyuan People's Hospital to study childhood leukemia in Sun Yat-sen Memorial Hospital of Sun Yat-sen University. After the study he returned to Heyuan to establish a children's leukemia professional group, so that Heyuan built up the ability to treat childhood leukemia. This will eliminate the difficulty and high cost of medical treatment in another city for patients from Heyuan. In Qinghai, we helped Qinghai Province retain the local leader in pediatric hematological diseases and avoided the brain drain.



In February 2019, Associated Love Program was officially launched in Qinghai. Wang Yubo, the member of the Standing Committee of the Qinghai Provincial Party Committee and executive deputy governor of Qinghai, attended the launching ceremony and delivered an important speech. New Sunshine Charity Foundation V Love Leukemia Special Fund contributes about 600 thousand US Dollars each year to set up a charitable medical insurance supplementary fund, which is equivalent to setting up a medical insurance of leukemia for 1 million children in Qinghai. The reimbursement ratio was made up to 90%, and the policy was officially implemented in September 2019. Till now, more than 20 children with leukemia has benefited from this program.



Summary

Using a multi-disciplinary professional approach, working closely with the government, focusing on solving problems from a mechanism level, Associated Love Program has achieved some success in the work on childhood leukemia.



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BACK

"My Opinion"



PROJECT "MY OPINION"

Aiming at providing clarifications and increasing the participation of people in the process of incorporation of new technologies into the health system, as well as improving the quality of contributions, FBH has created the project My Opinion. The project includes interactive and intuitive tools to facilitate learning and promote social participation in public consultations.

METHODOLOGY:

- Creation of a webseries with short animated videos;
- Development of a website for the campaign;
- Use of FBH social media to disseminate all the content created.

MAIN RESULTS:



The largest public consultation in 2019 in terms of technical contributions in Brazil



The 2nd largest public consultation in 2019 in terms of experience and opinion in Brazil

OVER 5 THOUSAND CONTRIBUTIONS



WEBSITE

907 page views | 639 visitors



FACEBOOK

17 posts | 10 images | 07 videos | 116.192 people reached

2.119 likes | 14.388 views



TWITTER

9 posts | without expressive database to show the results



INSTAGRAM

17 posts | 12 feed | 05 IGTV | 575.693 people reached

899 views | 148 double clicks

were sent to the public consultation about the inclusion of Emicizumab in the treatment of hemophilia-A with inhibitor of factor VIII who did not respond to the immune tolerance induction (ITI).

Scan this QR Code and visit My Opinion website:



hemofiliabrasil.org.br

/Hemofilia

[federacaobrasileiradehemofilia](https://www.instagram.com/federacaobrasileiradehemofilia)

HemofiliaBR



FEDERAÇÃO BRASILEIRA DE HEMOFILIA

Tania Maria Onzi Pietrobelli
PRESIDENTE



BACK

Using (HOPE Passport) as PHC tool to enhance cancer patient's self-management

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Hope Foundation For Cancer Care
Shih-ming Tsai
Digitalisation of Healthcare
ONCOLOGY, PAN-ONCOLOGY
Taiwan

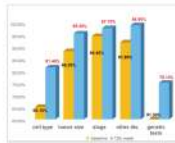
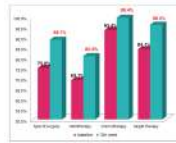
1. HOPE passport as a PHC tool

HOPE launch "HOPE passport" handbook in 2003. It is a Personal Health Care (PHC) tool to let patients and their families record some important data such as medicine, treatment plan, weight change, lab exam data and image results, side effects and health checkup date.

It can assist cancer patients to acquire self-management behavior during and after treatment are helpful to maintain a healthy status.

HOPE PASSPORT

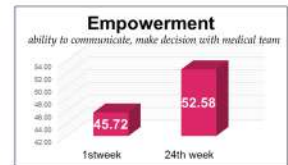
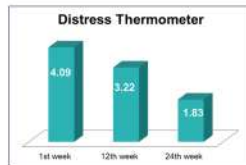
希望護照



2. Evaluation of HOPE passport

In 2016, through the evaluation research of 314 HOPE passport users, it confirmed that HOPE passport can raise patients' knowledge of treatment and build up self-management ability, further improve emotional and physical distress.

Source of the materials : Huang, Hsiang-Ping, RN, PhD, 2018 Union for International Cancer Control abstract



Empowerment, self-management and physical/emotional distress

Caregiver

My mother-in-law was diagnosed with pancreatic cancer. She went to emergency room at night few years ago. We showed HOPE passport to the ER doctor to understand her situation immediately. I think HOPE passport very useful for patients and families.



3. Benefit

HOPE passport handbook can raise patients' knowledge of treatment strategy and build up self-management ability, further improve emotional and physical disturbance. It is a useful PHC tool to accompany patients' treatment journey.

4. HOPE passport App Launched 2018 !

Due to digital trend we developed the "HOPE passport App" in 2018. We will also initiative an evaluation research this year in order to enhance the APP. There are more than 1,893 users until end of 2019.

Patient

It is not always convenient to take the book. It would be better if HOPE passport can transform to digital tool. I can record on my cell phone anytime.



HOPE passport APP interface

5. Keep promoting the APP

We held many promotional activities to let more patients and caregivers know the app and download. Furthermore, We promoted the app through the cancer case managers from different hospitals training courses.



Welcome to give us feedback !

Contact Sammy Tsai : sammy@ecancer.org.tw



HOPE FOUNDATION FOR CANCER CARE

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BACK

Multiple Sclerosis



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Multiple Sclerosis South Africa

Sherene Du Preez

Engaging in Healthcare Transformation

NEUROSCIENCE, MULTIPLE SCLEROSIS

South Africa

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BACK



Mundo Cáncer

mundocancer.com

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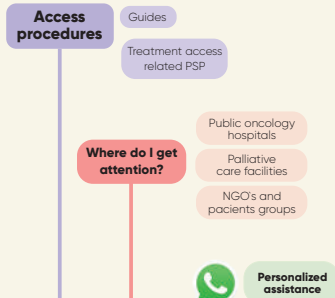
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Donde Quiero Estar

Maria de San Martin

Digitalisation of Healthcare
ONCOLOGY, PAN-ONCOLOGY
Argentina

MUNDOCANCER is an argentinean website that unifies and centralizes **reliable and safe information** about cancer, diagnosis, testings and treatments. It is supplied by official organisms, such as The National Cancer Insitute, Health Ministry, Drug Bank and experts, so that people with cancer and their families have the needed tools to **speed up treatment access times** and **improve their quality of life**.



Objetive

Centralize and unify information to assist people with cancer and their families in their cancer treatment acces and the available services that improve their quality of life.

Problematic

In Argentina exists a fragmented health service where different types of coverage coexist. More than 33% of the population attends within the public health system.

The information to start treatment, studies and medication is scattered or confusing, which doesn't allow patients to access their treatment in time and form.



“ Thank you from the bottom of my heart for responding and offering your help. Thank you very much for your answers to my questions. You are angels. ”

Family of patient with breast cancer.

Results

*jul '19 - Feb '20

5500

visits

151

consultations

196

access cases

Objetive 2020

Expand the procedure guides for treatment access to all the provinces of the country.

Powered by dondequieroestar.org





BACK

MAMatch!: a journey-sharing experience - Bringing patients together through technology

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FEMAMA

Maira Caleffi

Digitalisation of Healthcare
ONCOLOGY, BREAST CANCER
Brazil

THE DIAGNOSIS

66,000 new cases of breast cancer in Brazil in 2020

When people feel alone, they often seek support through dating apps

+ Lack of cancer-centred apps in Brazilian app stores

HOW IT WORKS

- Swipe right or left to choose to chat and engage with people
- Find the nearest NGO for assistance and support
- Find out news about cancer through push notifications sent by FEMAMA
- Talk to Fe, a chatbot about breast cancer and patient rights

THE GOAL

To match profiles with similar interests, just like 'Tinder'

Encourage people who face breast cancer to

SHARE

doubts, challenges, learnings, victories, find support and know their rights

WHAT WE DID

FEMAMA's October Pink 2018 campaign

Share your Fight

And what is the best way to share your cancer fight? Through an app!

MAMA* + MATCH =

MAMatch!

* "mama" means "breast" in Brazilian Portuguese

THE RESULTS

1,700 active members registered

More than **70** NGOs around Brazil available to match, give support and chat

New FEMAMA's tool for activating campaigns and sending push notifications

WHAT WE LEARNED

1. There was a lack of knowledge about the support of institutions and other people who understand their challenges
2. The importance of the presence of NGOs working in the cancer field **mobile apps**
3. Information about consumption habits of the audience in order to determine the most effective way to penetrate the market, and therefore increase **brand value and impact**.



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BACK

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FedEmo Onlus (Federazione delle Associazioni Emofilici Onlus)

Enrico Ferri Grazi

Digitalisation of Healthcare

RARE DISEASE, HEMOPHILIA

Italy



Italian Federation of Hemophilia Societies

Introduction

Punto e (Progetto Insieme) was designed and implemented to cover several areas of unmet need of the Italian Haemophilia community and was created through a collaboration between FedEmo, Roche and Helaglobe.

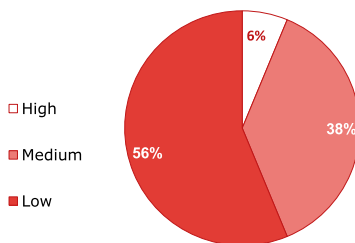
Online presence

Online presence is one of the weak links in the chain of communication between the local societies and the Haemophilia community. Most (56%) local societies have a low activity and online presence demonstrates this (Figure 1).

Low activity and lack of regular updates ultimately affects the patients, who cannot access important basic information or access FAQs.

The fragmented territorial presence of local societies implies a local focus and difficulties in communication and activity integration.

Figure 1. Online presence and activity



Approach to patient representation

The approach to patient representation has historically been focused on a "caring" approach, offering direct support with the available resources. The allocation of resources, on the other hand, has switched towards a more cost-effect attitude, rendering using such approach on its own obsolete. It now needs to be paired with an "advocacy" approach, represent members of the community in front of and decision makers, with the aim of influencing policies to improve care and quality of life for the community as a whole.

The needs of the patients

Haemophilia patients have four basic needs complementing care under the umbrella of preventive care:

1. Trusted dental care
2. Sport medicine
3. Physiotherapy
4. Basic information about Haemophilia preventive care

It then becomes increasingly important to provide accurate information as to where and how to access resources meeting these needs.

Project rationale

The rationale of the project is to enhance the online presence of the federation and the local societies, facilitating communication between them and the members of the community about internal announcements, as well as disseminating important information about scientific innovations.

The project envisages the implementation of a purpose-built platform (*Punto e*) to allow better communication between FedEmo and local societies through a log-in section of the website. Additionally, the log-out section, has the objective to provide a chance for patients to educate themselves further (through an e-learning platform on the society activities), create an external network with specialised physicians, Haemophilia treatment centres (HTC) and other care professionals (caregivers, dentists etc.) who have the expertise to treat haemophilia patients.

Punto e also allows societies to directly contact FedEmo through a direct line of communication, "FedEmo risponde" ("Fedemo answers").



Implementation and timeline

Log-in

Main characteristics of the platform:

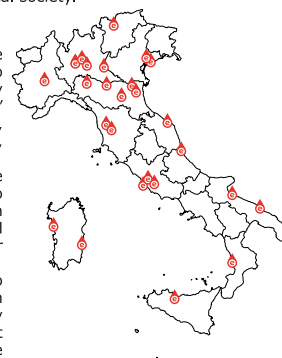
1. Tool optimized for both **mobile** and **desktop** devices
2. National and regional levels
 - . **National level** with FedEmo branding
 - . **Regional level** with a website section for each local society
3. **Engagement** with the members of the community
 - . Creation of value through the **sharing of scientifically accurate information** and institutional and scientific updates with the community. It also allows the society to let the community know which ones of its members completed the training course.
 - . **Training** of local trustees through the built-in e-learning platform through video classes followed by a test on topics such as:
 - . National Healthcare System
 - . Society management
 - . Fundraising 101
 - . Organizational designs for chronic diseases management
 - . Communication in the healthcare sector
 - . **Access to direct line of communication** with FedEmo with an available tutor to solve any administrative, organizational and institutional issues that may arise as a result of the limited resources of local society.

Log-out

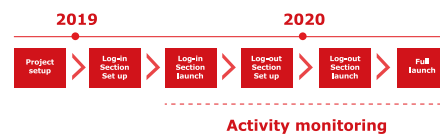
A national database will be developed to help patients identify "points of interest" (HTCs, dentists, physiotherapists, etc.).

Such database will be developed by FedEmo in collaboration with the local societies and trade associations for care professionals.

Users will be able to access the information directly through only one platform that pools all the information from local societies and FedEmo.



Users will be able to register and interact with the platform (all data remains within FedEmo, in accordance with GDPR laws), providing feedback on the information available on the website as well as on the quality of care and/or advice received. Such feedback is received by FedEmo and quality checked before a database update. Such immediate information is extremely important to allow FedEmo and local societies to swiftly intervene to resolve a potential issue.



Timelines

As of October 2019, 28 of the 32 local societies have registered to the platform and 18 have shared news and content in both the log-in and log-out section of the website.

2020 will see the roll-out of many of the log-out sections of the website including the user feedback section.

For more information:

- <https://fedemo.it/>
- <https://puntoe.fedemo.it/>
- [@FedEmoGiovani](https://www.facebook.com/FedEmoGiovani)

follow us

The project was supported by an unrestricted grant by Roche

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BACK

The Underestimated Burden Of Hereditary Cancer

Ana Rolo & Tamara Milagre

Associação EVITA: Edifício C. C. Continente de Telheiras | Av. Das Nações Unidas, Piso 2, Escritório 4 | 1600-528 Lisboa | PORTUGAL | info@evitacancro.org | T +351 935 047 027 | www.evitacancro.org



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EVITA
Ana Rolo and Tamara Milagre evita
Digitalisation of Healthcare
ONCOLOGY, HEREDITARY
Portugal

Abstract

Hereditary cancer (HC) is located in multiple organ systems and linked to the most frequent and most lethal cancers. It generally strikes at an early age, during the peak of the patient's productivity and often during childbearing years. It is therefore also the most expensive cancer. If the patient is unaware of their genetic predisposition, the cancer signs may be disregarded by the self or even by health care practitioners, leading to diagnosis at late stages and poor prognosis. Nevertheless, with adequate measures, HC has the potential to be one of the most avoidable and early detected cancers. Identified mutation carriers can choose to undergo early and frequent screening, as well as prophylactic surgery. Here we identify the most prominent unmet needs in the treatment and prevention of HC, which are: lack of data, under-identification of mutation carriers, waiting times for testing and surgeries, need for genetic panel testing, information on oncofertility and pre-implantation genetic testing, and lack of resources. We propose measures to address these needs, and list several fronts on which our association, EVITA - Hereditary Cancer, works to improve these gaps raising the value in healthcare in Portugal.

Unmet Needs in Hereditary Cancer

1. Lack of data

The Portuguese National Cancer Register (RON - Registo Oncológico Nacional) does not specify data about HC. There are small registries worldwide, but they are not interconnected. Collection of data and its analysis is the way forward to understand the many aspects of HC and create solutions.

There is also the need to continue basic and clinical research on all aspects of HC.

- EVITA is a part of ERN GENTURIS [B]
- EVITA sponsors and supports continued research on HC [C, D, E, F]

2. Unidentified mutation carriers

According to the coordinator of ERN GENTURIS, Nicole Hoogerbrugge, only 20-30% of HC mutation carriers are identified. This can be due to lack of evident family history (for instance, due to small family size and/or breast cancer mutations inherited from the paternal side). However, there is a generalised lack of information regarding HC in Portugal, and people with an obvious family history are not aware that they may qualify for genetic testing.

"To identify a woman as a carrier only after she develops cancer is a failure of cancer prevention".
Marie-Claire King

- EVITA recommends that all Portuguese women over 25 years old be tested for BRCA2-P
- EVITA co-sponsors the ASPIC study on the Portuguese founder mutation [G]
- EVITA conducts awareness campaigns in the media and through social networks [H, I, J, K]

3. Waiting times

There are mutation carriers in Portugal who develop cancer whilst waiting for genetic consultation, testing or prophylactic surgery.

- EVITA has recently conducted a survey to assess the reality of genetic testing and waiting times in the Portuguese population [L]
- EVITA is sponsoring a study on the economic burden of HBC, aiming to alert the powers-that-be for this reality [M]

4. Gene panels

Around 30% of hereditary breast cancers are negative for BRCA1/2. Gene panels are recommended to detect non-BRCA genes, and variants of unknown significance need to be further tested.

- EVITA recommends thorough studies on risk management for all the genes in the panel

5. Pre-implantation genetic testing and oncofertility

Given the early onset of most HC, preservation of fertility is often a key issue for patients. They should be informed of their fertility preservation options.

- EVITA recommends that mutation carriers be advised of their reproductive options immediately after getting the genetic test result and/or cancer diagnosis
- EVITA is preparing an information leaflet about pre-implantation genetic diagnosis procedures

6. Lack of resources

There is a generalised lack of resources to support the rising number of identified mutation carriers

- EVITA recommends the improvement of infrastructures and reinforcement of human and technical resources to fight the increase in incidence and early deaths from HC
- EVITA collaborates with all relevant stakeholders and constantly lobbies for the importance of HC screening and prevention

[A] EVITA platform

Together with Prologica, we are working to build an online evidence-based registry for carriers of genetic mutations with high cancer risk in Portugal and, at later stages, worldwide.

This will:

- Help patients and health carriers, as well as their families, to understand and manage their risks.
- Create the first registry of the disease in the family (including building a genealogy), thus helping citizens evaluate the risk and leading to a personalised genetic approach, early diagnosis, risks, or treatment.
- Increase awareness and generate knowledge about HC incidence and prevalence to promote epidemiological studies.
- Increase health literacy and provide information accessible to the lay person, as well as the HCPs.
- Offer additional services and support to improve the quality of patients and health carriers.

[B] ERN GENTURIS

A European Reference Network (ERN) is a network connecting healthcare providers and centres of expertise (including building a genealogy), thus helping citizens evaluate the risk and leading to a personalised genetic approach, early diagnosis, risks, or treatment.

- Improved identification of people living with a genetic tumour risk syndrome (genturism)
- Reinforced education in clinical practice and outcomes
- Development of evidence-based clinical guidelines
- Development and use of patient registries, biobanks and research tools
- Defined health care pathways to facilitate improved access to international specialist clinical knowledge for patients and their families throughout the EU
- The European Development and use of patient registries, biobanks and research tools

Evita recommends joint collaboration with ERN GENTURIS and the reinforcement of National GENTURIS Reference Centers

[C] RISK FACTOR ANALYSIS OF HEREDITARY BREAST AND OVARIAN CANCER

EVITA is sponsoring the extension to Portugal of Dr Steven Narod's study "RISK FACTOR ANALYSIS OF HEREDITARY BREAST AND OVARIAN CANCER", which through medical and lifestyle questionnaires has been aimed at understanding risk factors in the development of cancer in carriers of BRCA and PALB2 mutations. This is a worldwide multicentre study which has been running since the 1990s and has currently enrolled around 20000 patients.

[D] Risk stratification in response to ionizing radiation in BRCA1- and BRCA2-associated Hereditary Breast and Ovarian Cancer

EVITA is supporting this study, undertaken by Professors Ana Margarida Abitona and Maria Fátima Simões at Faculty of Medicine, University of Coimbra (Coimbra, Portugal), which aims to understand the risks of exposure to radiation in cells carrying mutations in BRCA genes. These cells will be isolated from donor carriers, and used in non-carrier healthy controls. This project will help understand the risks associated with exposure of carriers to radiation commonly used in routine medical procedures using ionizing radiation.

[E] Exploring Glyco-mucin Biomarkers for Serum Diagnosis of Ovarian Cancer Patients

EVITA supports this study by the group of Dr Carmo Dado and Dr Sara Ricardo at IPATMUP (Porto, Portugal), which aims to develop a new serum biomarker for ovarian cancer with higher specificity than the currently used one (CA125). Preliminary results show that this biomarker has the potential to significantly increase specificity and sensitivity for discrimination between benign / borderline / malignant serous ovarian tumours.

Early detection of ovarian cancer is a major issue for BRCA mutation carriers, which undergo early menopause due to prophylactic oophorectomy in their late 20s. The promise of a more sensitive and specific biomarker may allow these women to undergo tight surveillance screening rather than being subject to prophylactic surgery.

[F] The Portuguese BRCA2 founder mutation: new tools to investigate the molecular mechanisms underlying cancer susceptibility

In collaboration with EVITA, the group of Prof Carmo Fomasa (MM, Lisboa, Portugal) is investigating how the Portuguese BRCA2 founder mutation disrupts normal cellular function. Using cells rescued from healthy carrier donors, this group has been able to create induced pluripotent stem cells (iPSCs) which will be grown in the laboratory and induced to differentiate into numerous progenitor cells. This model will allow the study of how mammalian cells respond to cancer inducing factors.



[G] PROGNOSIS OF BREAST CANCER ASSOCIATED WITH THE PORTUGUESE BRCA2 FOUNDER MUTATION c.156_157insA
EVITA supports and sponsors this study by ASPIC (Portuguese Association of Research in Cancer) which aims to:

- Describe the overall and cancer specific survival implications of BRCA2-associated breast cancer when compared to non-BRCA mutated breast cancer or unknown BRCA status breast cancer.
- Describe the demographic, clinical and pathological characteristics of BRCA2-P-associated breast cancer



[H] saBeR mais ConTA (knowing more matters) campaign

This ongoing campaign started in May/2019. Ovarian Cancer World Day. It aims to increase awareness amongst clinicians and lay people of the importance of identifying carriers of BRCA mutations. It is a health and cancer risk. It is essential for patients, as it directly impacts therapeutic decisions, and also because it allows the identification of other family members who are healthy carriers, which should undergo tight cancer screening and may be for prevention purposes.

The saBeR mais ConTA campaign is run together with the relevant medical societies.



[I] Breast Cancer in Men

Men can get breast cancer (BC) too. One in every one-hundred BC occurs in males, and a male BRCA2 mutation carrier has a 10x higher to develop BC than a non-carrier. Male breast cancer frequently has poor prognosis due to late stage diagnosis. This is mainly due to the fact that there is a generalised lack of awareness surrounding male BC.

EVITA was a media campaign, including TV ads, in which the famous Portuguese male model Bruno Quares performed. The content to run posts on social media regarding this topic.



[J] "Tenho cancro, E depois?" ("I have cancer. Now what?") campaign

The word cancer is still somewhat a taboo in Portugal. Even nowadays, we often hear in the news that he and she died after a prolonged illness, which invariably means cancer. The campaign "Tenho cancro, E depois?" aims to destigmatise the word cancer through explaining its causes and putting people at the centre of the problem, giving cancer a face. Talking openly about cancer is the best way to start preventing and curing the disease.

EVITA is part of the board of curators of relevant stakeholders in this campaign.



[K] "O Futuro Já Começou" ("The Future Has Already Started") campaign

"The Future Has Already Started" aims to aid research on cancer based on precision medicine. This campaign is an extension of the strategic plan for the implementation of precision medicine in Portugal. Its goals are to inform the public about precision medicine and the need for personalised treatments, given that each individual is unique. The Portuguese Association of Hospital Administrators (APHA) and ET are partners of EVITA in this campaign.



[L] Genetic diagnosis online inquiry

EVITA, together with IQiA, has conducted an online questionnaire to understand the main difficulties and obstacles reported by patients before and after undergoing genetic testing. The main issues identified were waiting times and the lack of information available.

The full results will be published in a scientific journal together with the results of a parallel questionnaire promoted by the Portuguese Oncology Society amongst HCPs.



[M] Financial Report of the Burden of Hereditary Breast Cancer

Hereditary Breast Cancer (HBC) represents up to 20% of all BC, and has excess mortality and morbidity due to typical early onset of disease and frequent late stage diagnosis. There is a need to quantify the economic burden of HBC to convince stakeholders and the powers-that-be of the need to optimise:

- access to diagnosis (avoiding underdiagnosis)
- treatment (avoiding overtreatment)
- delivery of high-quality health care (best practice options)

Together with Nova School of Business and Economics (Nova, Portugal), we are working on elaborating a Financial Report of the Burden of HBC.



BACK

Patient Registry and Follow-up System for Turkish SMA Patients

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Rationale

Lack of up-to-date patient data

University-based small registries do not add value

Method

Based on several touchpoints

Three main phases

Results

Up-to-date patient data

Not a replacement for official patient database

SMA Benimle Yürü

Olcay Korol
Digitalisation of Healthcare
RARE DISEASE, SPINAL MUSCULAR ATROPHY
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Process



150 type-1 patients
200 type-2 patients
250 type-3 patients

Total of 600 patients followed-up
Almost half of national database

This poster complies with the laws/regulations of Turkey

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