

Towards the development of a national
genomics strategy in Ireland

SAPHIRe Workshop
17th October 2019

**Research.
Evidence.
Action.**

HR^B Health
Research
Board

Overview of Irish Health System

- Budget *from Government* > €16 billion in 2019 (or ~25% of total Government spend)
- Mixed model: public and private
 - Medical care scheme offers free public health services (36% of population)
 - GP card offers free GP services (10% of population)
 - Remainder pay for GP visits, medicines etc
 - 46% have private health insurance
- Hospitals currently organised around 7 Hospital Groups (each with at least one major University Teaching Hospital + primary academic partner)

Sláintecare

- Ten year reform programme for health system
- Organised around six new regional health bodies
- Responsible for organising and delivering health and social care in the regions

Vision: *“the right care, in the right place, at the right time”*



Regional Health Area F

- Galway CRF

Regional Health Area E

- University Hospital Limerick

Regional Health Area D

- Cork CRF

Regional Health Area A

(pop. 1,080,000)

- Mater University Hospital ?
- RCSI CRC - Beaumont Hospital

Regional Health Area B

- WT-HRB-CRF St. James's Hospital

Regional Health Area C

- UCD CRC (St Vincents)

Key changes:

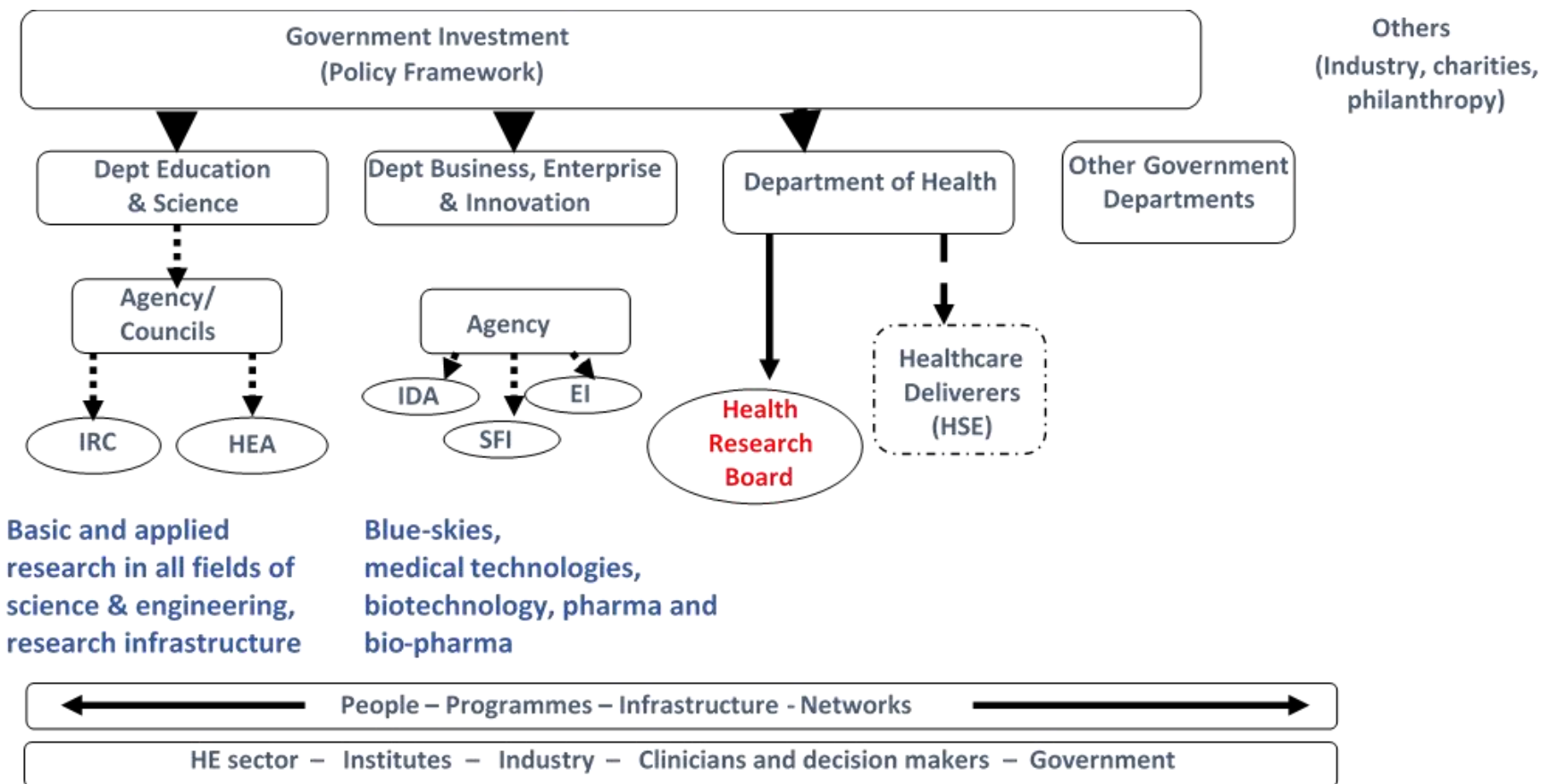
- Dublin is now divided geographically – biggest change is that the Mater and St Vincent's are separated.
- Cork and Waterford relationships

- Our Lady's Children's Hospital Crumlin falls under "Children's Health Ireland" and the National Paediatric Development Board.

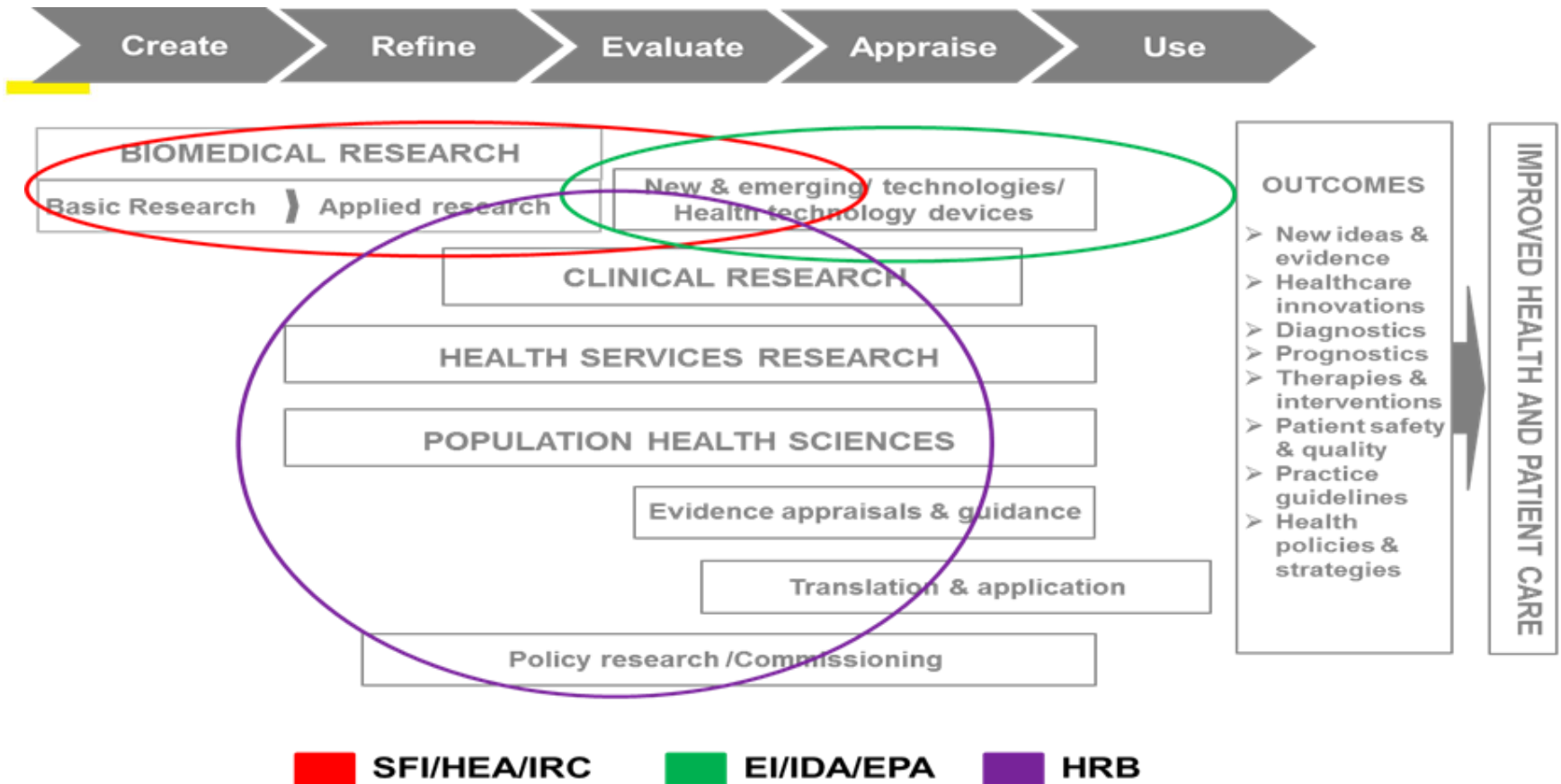
Focus of Sláintecare....

- Improve population health-based planning
- Develop new models of care to deliver more effective and integrated care
- Expand community-based care to bring care closer to home
- Develop and modernise the acute care system
- Expand eligibility on a phased basis to move towards universal healthcare
- Ensure the health system is financially sustainable; reform funding system
- Implement measures to address inequities in access to public acute hospital care
- Establish a National Health R&D Forum

Overview of Health Research Landscape



Positioning of Irish research funding agencies along the health research continuum



HRB Basics.....

- State agency under Department of Health.
 - Budget ~€45m pa (0.3% of health budget), funding portfolio €150m+, staff of 65
- Providing evidence for policy
 - Public Health Alcohol Bill, Food Pyramid, Fluoridation
- Information for service planning
 - Drug use, disability, mental health
- Funding health research
 - Clinical, Population Health, Health Services Research
 - Infrastructure, capacity building, specific projects.



intramural

extramural

Main issues for clinical research in Ireland

- Infrastructure still relatively new
- HSE does not have a dedicated budget line for research
- Research funded through agencies, some private funding, charities
- Links between hospitals and universities under development
- Limited protected time for research
- Research governance within health system under review – R&D strategy currently being developed

Context for personalised medicine

- **Technology:** digital revolution in health; novel computational approaches; ability to analyse and to link large datasets; complete decoding of the human genome; rapid sequencing and analytical techniques
- **Different approach to healthcare:** the starting point should not be the disease but the patient, with his or her individual characteristics; drive towards prevention and early intervention
- **Sustainability of healthcare systems:** increased costs and complexity; drive for better use of resources
- **Societal expectations:** more informed and engaged patients; expectation of improved health related quality of life
- **Opportunities** – for patients, healthcare providers, payers, industry

National Genomics Strategy / Action Plan

- Building on review of genetic services in Ireland (2014) + the national genetic and genomic medicine strategy group
- Recommendation:
 - Establishment of national genetics and genomics medicine network
 - National Director of Network being recruited (joint HSE / UCD / TCD)
 - Appointing a Clinical Director (Genetic and Genomic testing)
- Work on strategy to begin in 2020 (R&D Forum)
- Scope: Healthcare and R&D

Points to consider....

- Implementation of genomic medicine in routine clinical care needs to be informed by:
 - Clear value for healthcare system and patients
 - Rationale for public and private investment
 - Clarity on roles, responsibilities and governance
 - Evidence on cost, cost effectiveness and sustainability
 - Legal and ethical considerations
 - Implications for biobanking and data infrastructure
 - Public acceptability

Personalised medicine research in Horizon 2020

Domains and attributes relevant for SC1

Cross-cutting issues / Policy areas	Disease areas	Scope of research / Intervention studied	Type of clinical study
<ul style="list-style-type: none">•Personalised medicine•Public health•Rare diseases•Antimicrobial resistance•...•[12 unique attributes]	<ul style="list-style-type: none">•Cancer•Cardiovascular diseases•Diabetes and obesity•Tuberculosis•...•[20 unique attributes]	<ul style="list-style-type: none">•Biomarkers•Medical devices•Drug•Somatic-cell therapies•...•[21 unique attributes]	<ul style="list-style-type: none">•Non-interventional•Non-drug interventional•Phase 1•Phase 2•...•[6 unique attributes]

Multiple attributes from each of these 4 domains can be selected for individual projects

Applicability of each attribute is clearly defined

SC1 projects per domain: *Cross-cutting issues / Policy areas*



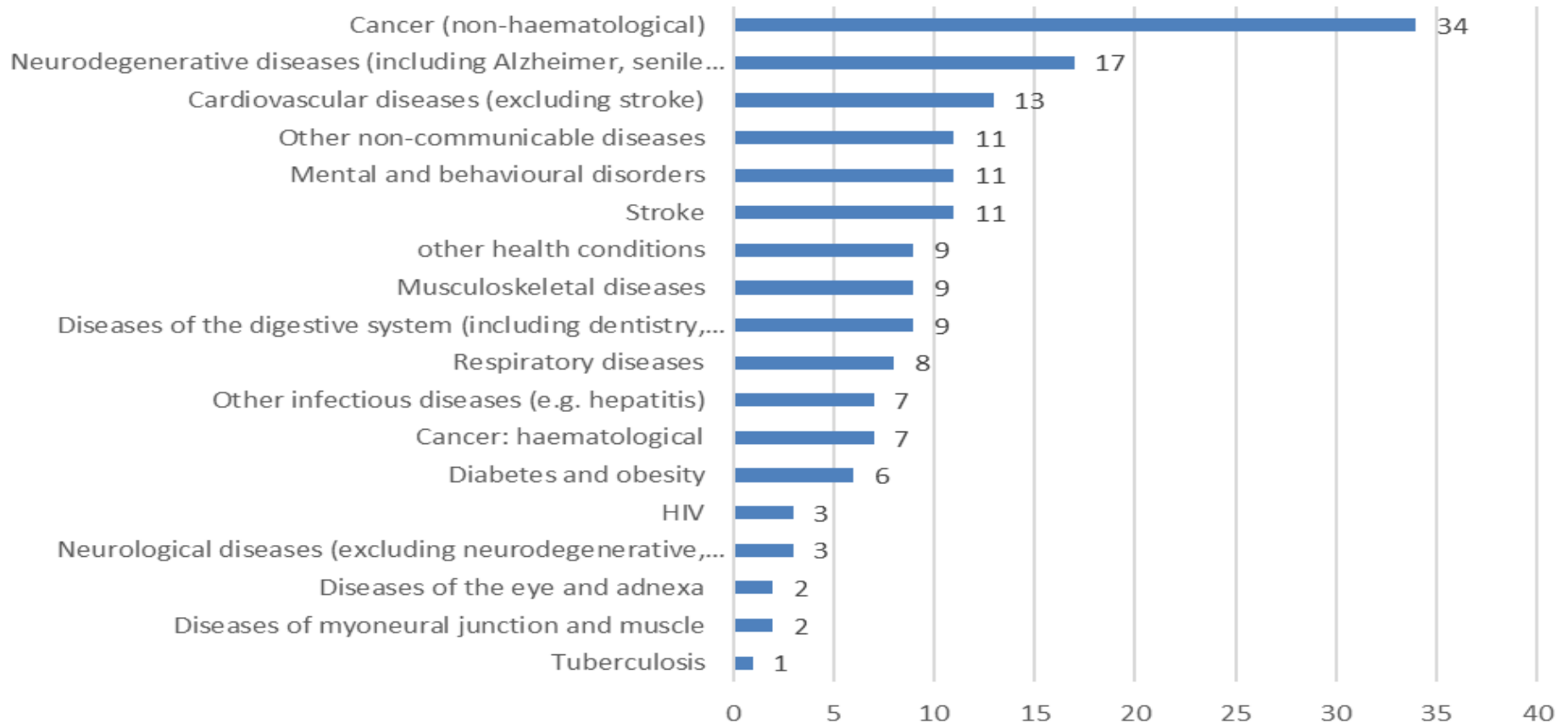
Number of projects	Cross-cutting issues / Policy area
140	Personalised medicine
129	Public health
117	ICT (including eHealth)
74	Healthy ageing
29	Paediatrics
27	Rare diseases
23	Comorbidities
14	Antimicrobial resistance
14	Environment (including endocrine disruptors, chemicals, pollutants, occupational medicine)
11	Maternal health and childbirth (i.e. pregnancy and the puerperium)
3	Alternatives to animals (better human safety testing)
2	Ethics

Personalised Medicine and disease areas

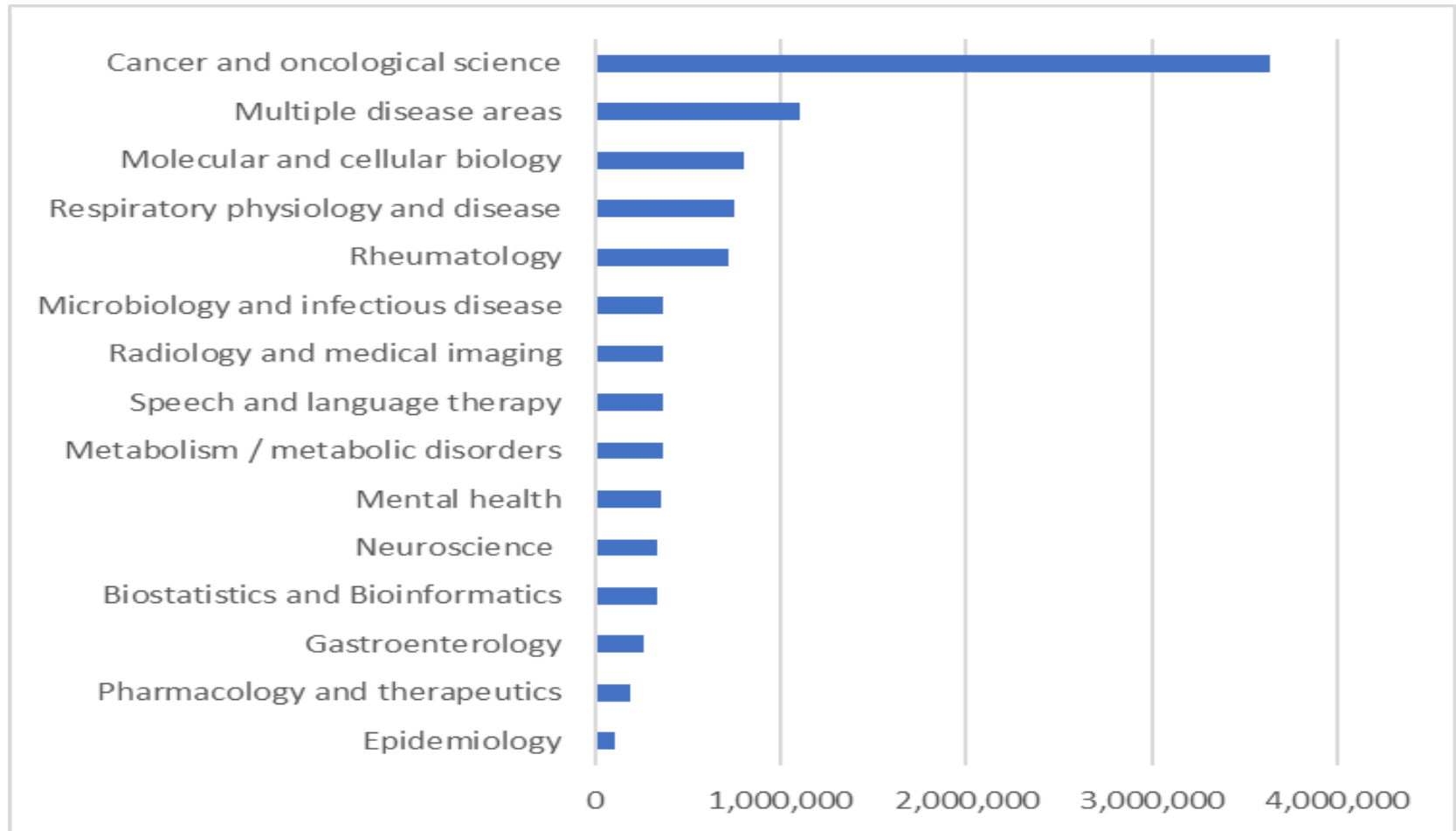


Which **disease areas** are targeted in projects where **personalised medicine** is a selected attribute?

of personalised medicine projects by diseases



HRB spend on personalised medicine research 2010-2018



The International Consortium for Personalised Medicine



Key milestones leading to ICPerMed

- 2010** Series of workshops organised by European Commission (with focus on 'omics' related research)
- 2011** Conference on European Perspectives in Personalised Medicine organised by European Commission
- 2011** Establishment of EuroBioforum (4 year project funded through FP7; platform for funders and performers in per medicine)
- 2013** Establishment of PerMed (CSA funded through FP7)
- 2015** Strategic Research and Innovation Agenda (SRIA) published by PerMed
- 2016** Personalised Medicine Conference organised jointly by European Commission and reps of member states (June)

~€2 billion for PM activities and projects through FP7 and H2020

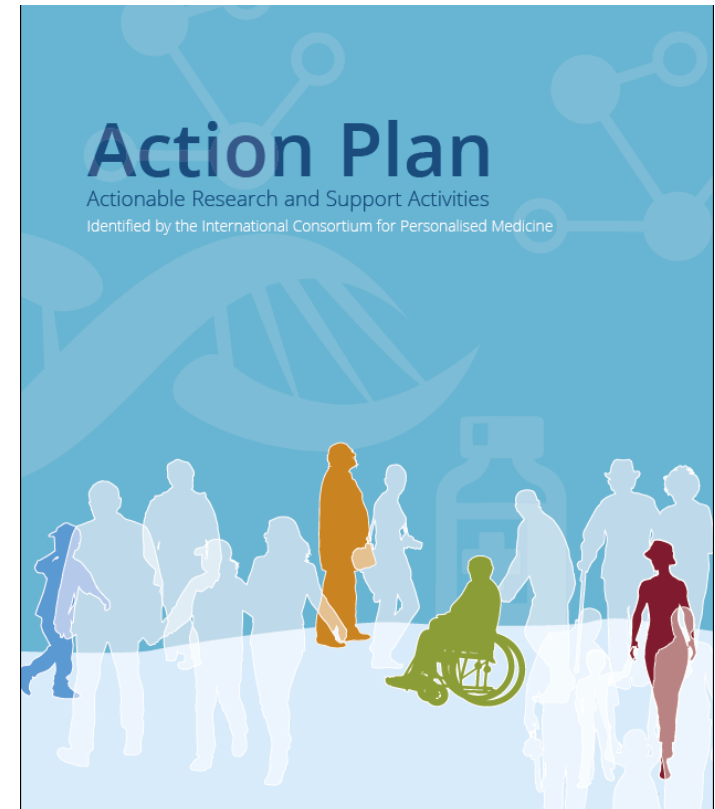
ICPerMed established November 2016

Aim: To coordinate and foster **research** to develop and evaluate personalised medicine approaches

- More than 35 European and international partners
- Representing ministries, funding agencies and the European Commission
- International Consortium model
 - Identify common strategic goals
 - Agree to share tasks (and costs) for coordination
 - Countries fund research according to their funding rules
 - Aim to share results, data, standards and examples of best practice

Action Plan

- Published in March 2017
- Identifies actionable research and support activities
- Used to inform the strategy of research funders at national and European level (e.g. ERA PerMed)

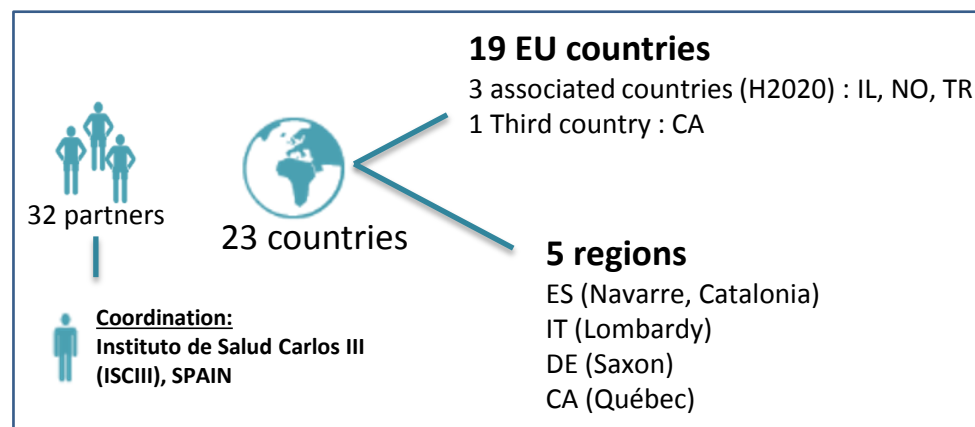


ERA NET on Personalised Medicine: ERA PerMed

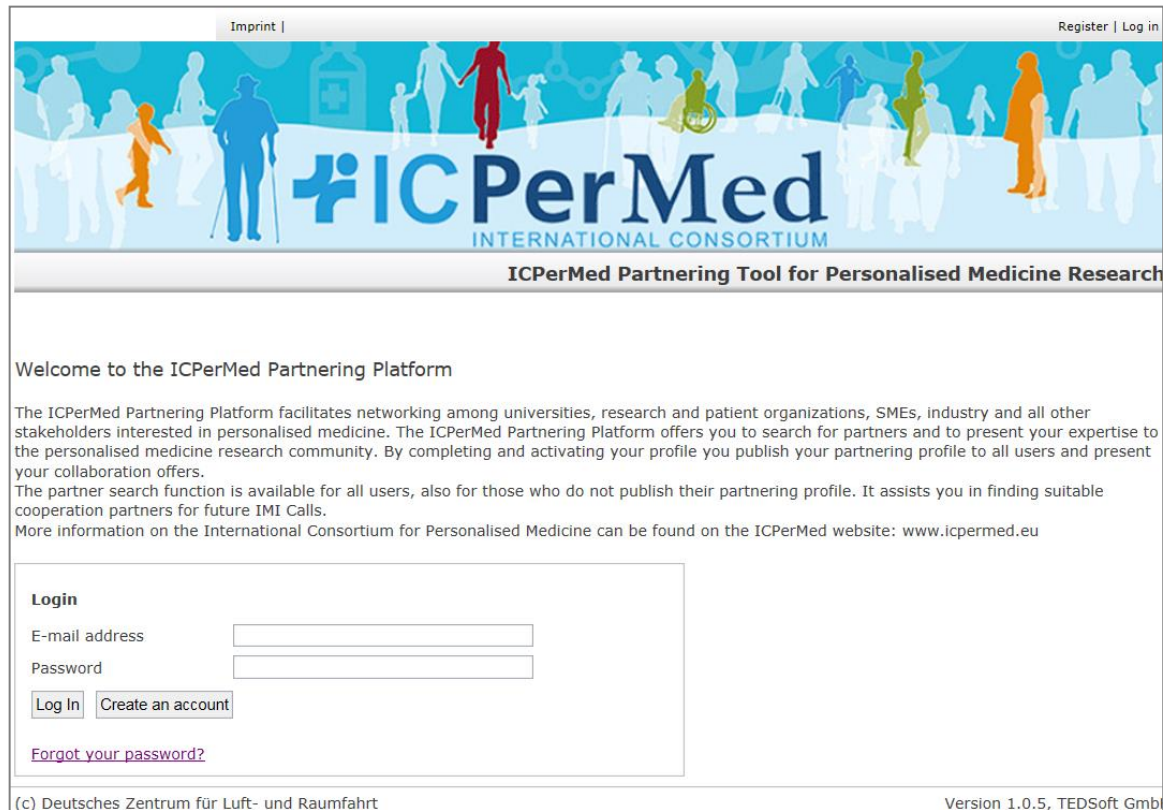
- **Runtime:** 1 December 2017 – 30 November 2022
- **Partners:** 32 funding organisations from 23 countries (AT, BE, CA, DE, DK, **ES**, EE, FI, FR, HR, HU, IE, IL, IT, LV, LU, NL, NO, PL, RO, SE, SI, TR)

- **Objectives:**

- Align national research strategies
- promote excellence
- strengthen the competitiveness of European actors in the field of personalised medicine
- strengthen European collaboration with third countries



Partnering Tool



Imprint | Register | Log in

ICPerMed
INTERNATIONAL CONSORTIUM

ICPerMed Partnering Tool for Personalised Medicine Research

Welcome to the ICPerMed Partnering Platform

The ICPerMed Partnering Platform facilitates networking among universities, research and patient organizations, SMEs, industry and all other stakeholders interested in personalised medicine. The ICPerMed Partnering Platform offers you to search for partners and to present your expertise to the personalised medicine research community. By completing and activating your profile you publish your partnering profile to all users and present your collaboration offers.

The partner search function is available for all users, also for those who do not publish their partnering profile. It assists you in finding suitable cooperation partners for future IMI Calls.

More information on the International Consortium for Personalised Medicine can be found on the ICPerMed website: www.icpermed.eu

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- Platform for research organisations and individuals to find potential cooperation partners
- E.g. used by ERA PerMed and Flagship Canada/EU call
- ~ 250 entries so far



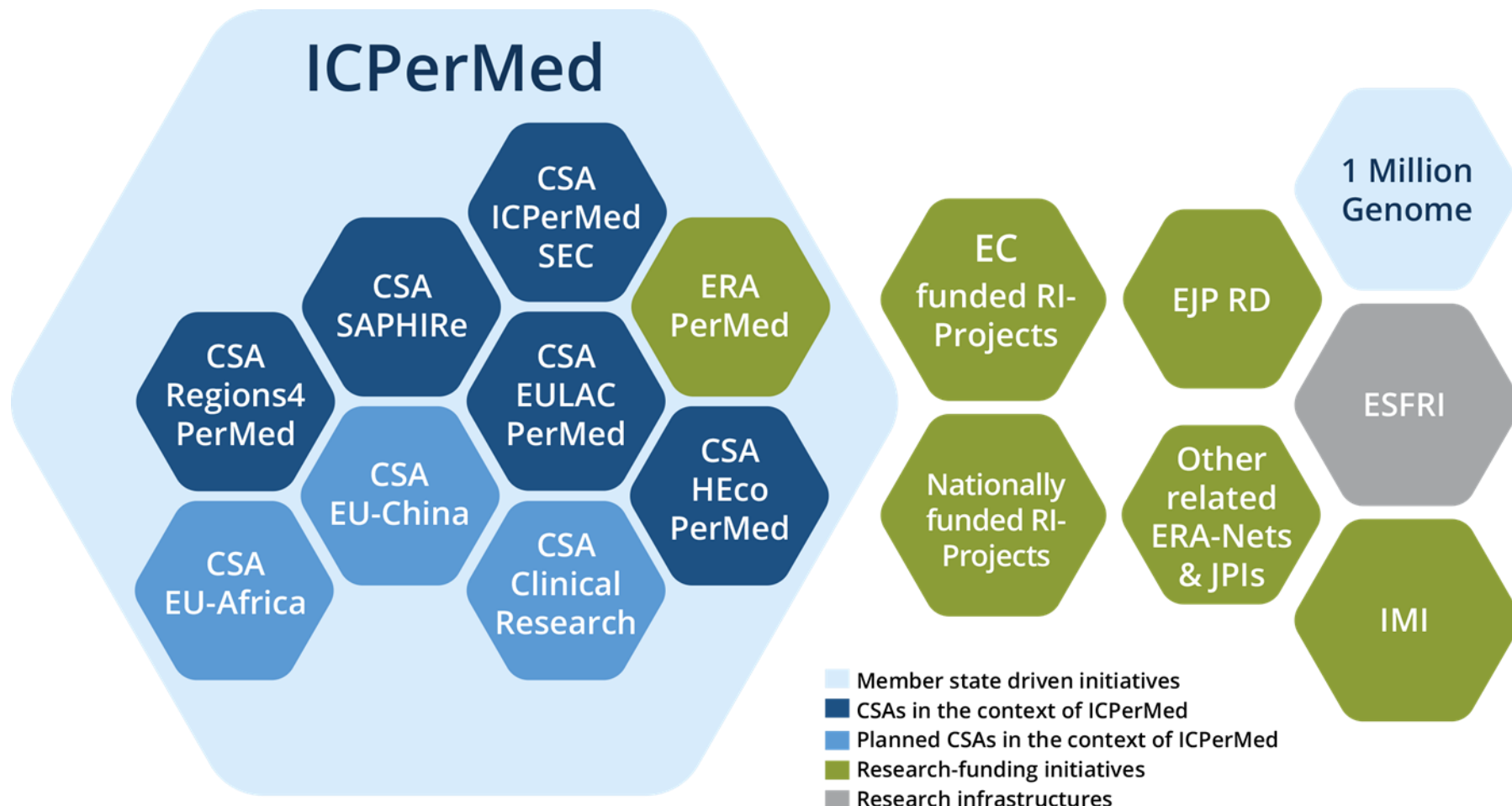
ICPerMed Workshop 2017

**Innovative Concepts on Data Generation and use for Personalised
Medicine Research**

ICPerMed Conference 2018
Personalised Medicine in Action

ICPerMed Workshop 2019
**"Personalised Medicine for all citizens and patients, with
sustainable implementation**

ICPerMed „Family“ and related initiatives



Actions in support of ICPerMed

CSAs that started in 2019:



Securing the adoption of personalised health in regions



Regions4PerMed

Interregional coordination for a fast and deep uptake of personalised health



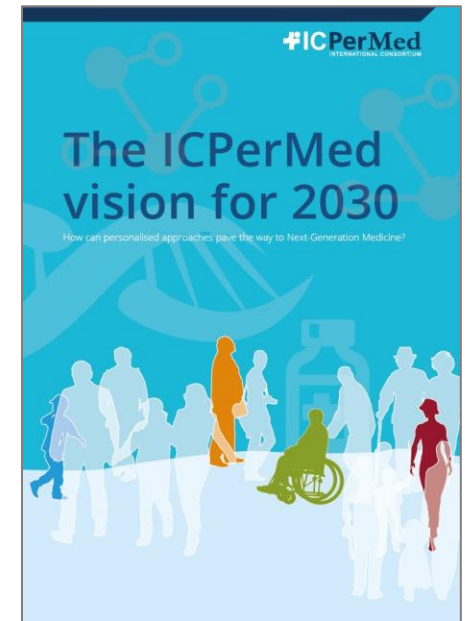
Widening EU-CELAC policy and research cooperation in personalised medicine



Healthcare- and pharma-economics in support of ICPerMed

ICPerMed Vision Paper

- Future vision of ICPerMed on personalised medicine research and implementation by 2030:
“How can personalised approaches pave the way to next-generation medicine?”
- Based on consultation of European and international experts, covering the entire range of relevant sectors and professional backgrounds
- Available for download on the ICPerMed website



ICPerMed Vision 2030

- Citizens have control over their health-related data and can access reliable and understandable sources of medical information easily
- Health providers keep up with rapid development in PM solutions and use health information and research results safely and responsibly
- Healthcare systems enable personally tailored and optimised health promotion, prevention, diagnosis and treatment
- Health related information for optimised treatment, care, prevention and research is available
- Economic value is established by innovative medicine, creating new jobs in healthcare systems and taking into account telemedicine and mobile solutions

Example: FutureNeuro *

Problem: 1 in 4 people in Ireland affected by a neurological disorder during their lifetime.

Aim: Develop new technologies and solutions for treatments, diagnosis and monitoring of chronic and rare neurological diseases

- Significant advances in genomic medicine
- Cost of genomic sequencing has reduced
- Recent advances in development of molecular therapeutics and biomarkers
- Availability of epilepsy electronic patient record (EPR): 10,000 people; clinical information + patient reported insights (meds compliance, quality of life, severity etc)
- Size of the healthcare system in Ireland: large enough for relevant results; but small number of linked clinicians to support a national collaboration

* SFI funded Centre

Example: Tailor X Study



Problem:

Which patients with early-stage ER/PR+/HER2- breast cancer are more likely to benefit from chemotherapy?

Most women with early stage breast cancer can avoid chemotherapy

- 15-year Trial involving >10,000 women; 690 recruited in Ireland (Irish arm of trial coordinated by Cancer Trials Ireland)
- Examined a methodology for personalising post operative cancer treatment
- Used a 21-gene expression test
- Identified that 70% women with low risk of cancer recurrence after surgery could avoid chemotherapy
- Now routinely offered as part of clinical care
- Generated considerable savings for HSE

Summary

- Health reform programme underway
- Director of National Genetics and Genomics Medicine Network being appointed
- Development of a National Genomics Strategy planned in 2020 (Health R&D Forum)
- Good European / international engagement
- Good programme level examples of personalised medicine research and links to healthcare system

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