



# INTERNATIONAL DATA SHARING COLLABORATION AND IMPACT

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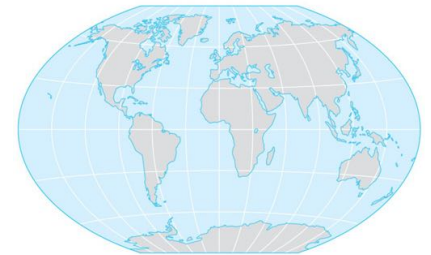
# OVERVIEW

## 1. International impact strategy



## 2. A tale of three international funders on a collaborative journey to data sharing

- Use of key four elements to maximize the use of Researchfish
- Exploring “proof of concept”



## 2. Lessons learned



## 3. Future directions

# 1. INTERNATIONAL IMPACT STRATEGY

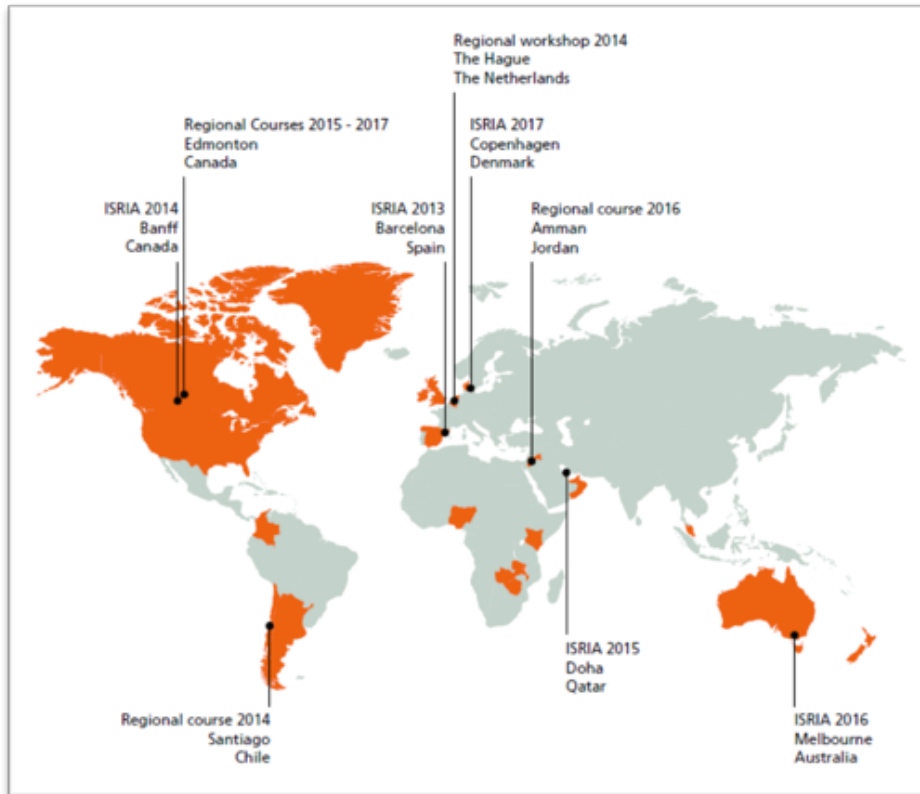
## A TALE OF THREE INTERNATIONAL FUNDERS

# SETTING THE INTERNATIONAL STAGE – IMPACT FIVE YEARS AGO

- Too academic and not practitioner focused debate
- Poor ongoing local debate and isolation of interested stakeholders except in few countries
- A nascent but diffused community of practice
- A need to build **international capacity, share practice and develop standards**
- A need to create a context where people could **learn from experts and peers**



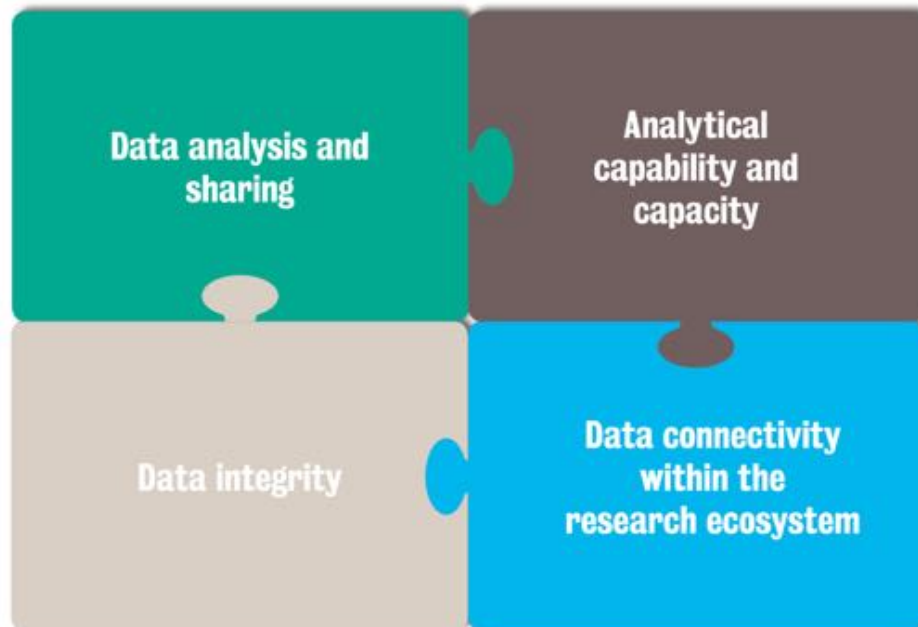
# FUNDERS CAME TOGETHER TO BUILD GLOBAL CAPACITY FOR LOCAL NEEDS....



[www.theinternationalschoolonria.com](http://www.theinternationalschoolonria.com)

The screenshot shows the website's navigation menu on the left and a main content area on the right. The navigation menu includes buttons for: Home, What is RIAT?, About The School, Commission, Thematic Groups, About the Center, Faculty, Hosts, Registration and Fees, Participants Area, and Faculty Resources. The main content area features a logo of wooden blocks, the title "The International School on Research Impact Assessment", and a section for the "Denmark course October 2017 - save the date!". Below this is a photograph of a large, modern building with a glass facade and a body of water in the foreground.

# WE WANTED TO MAXIMIZE THE USE OF RESEARCHFISH DATA



*We had to start with a “safe harbor” of trust as there was no established roadmap for us to follow*

# ISRIA PROVIDED A COMMON LANGUAGE

## SHARED TAXONOMY AROUND PURPOSE

To support the development of effective funding strategy

To promote responsible management of funds



4 A'S OF  
RESEARCH IMPACT  
ASSESSMENT

To demonstrate the benefits of research, education and innovation to society

To answer questions about 'what works'. Make improvements based on data

Jonathan Grant  
King's College

# USE OF KEY FOUR ELEMENTS TO MAXIMIZE THE USE OF RESEARCHFISH



# SHARED UNDERSTANDING



1 Data analysis and data sharing



Provide a 'safe harbour' for sharing of data to encourage data sharing across multiple funders



 ALBERTA INNOVATES



  
National Institute for Health Research



novo nordisk fonden

## ALBERTA INNOVATES

To be indisputably recognized as a leader – provincially, nationally and internationally in catalyzing R&I in Alberta

## NIHR

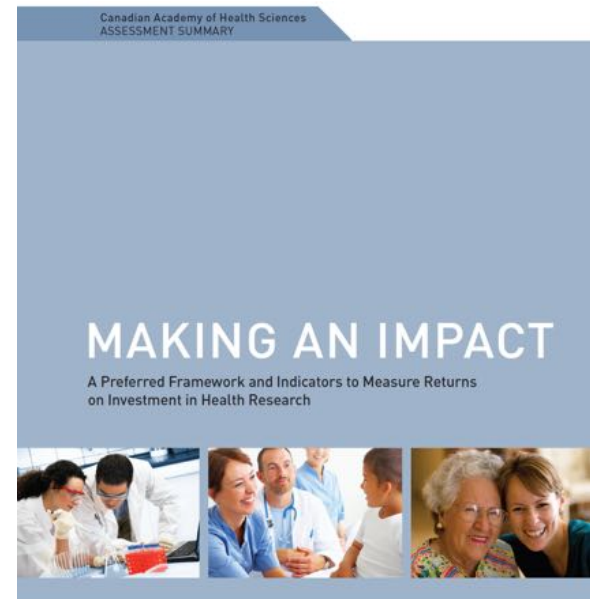
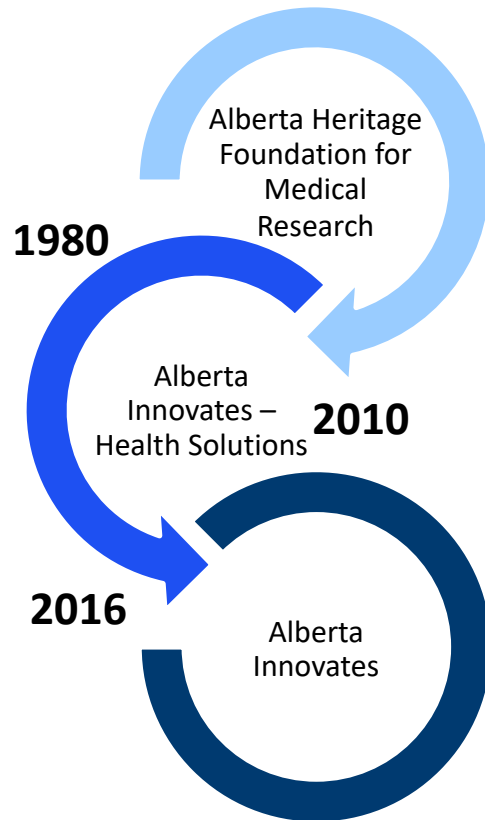
To improve the health and wealth of the nation (UK) through research

## NOVO NORDISK FOUNDATION

To contribute significantly to research and development that improves the lives of people and the sustainability of society.

# ALBERTA INNOVATES AND CANADIAN CONTEXT

Our mandate includes a “focus on outcomes”



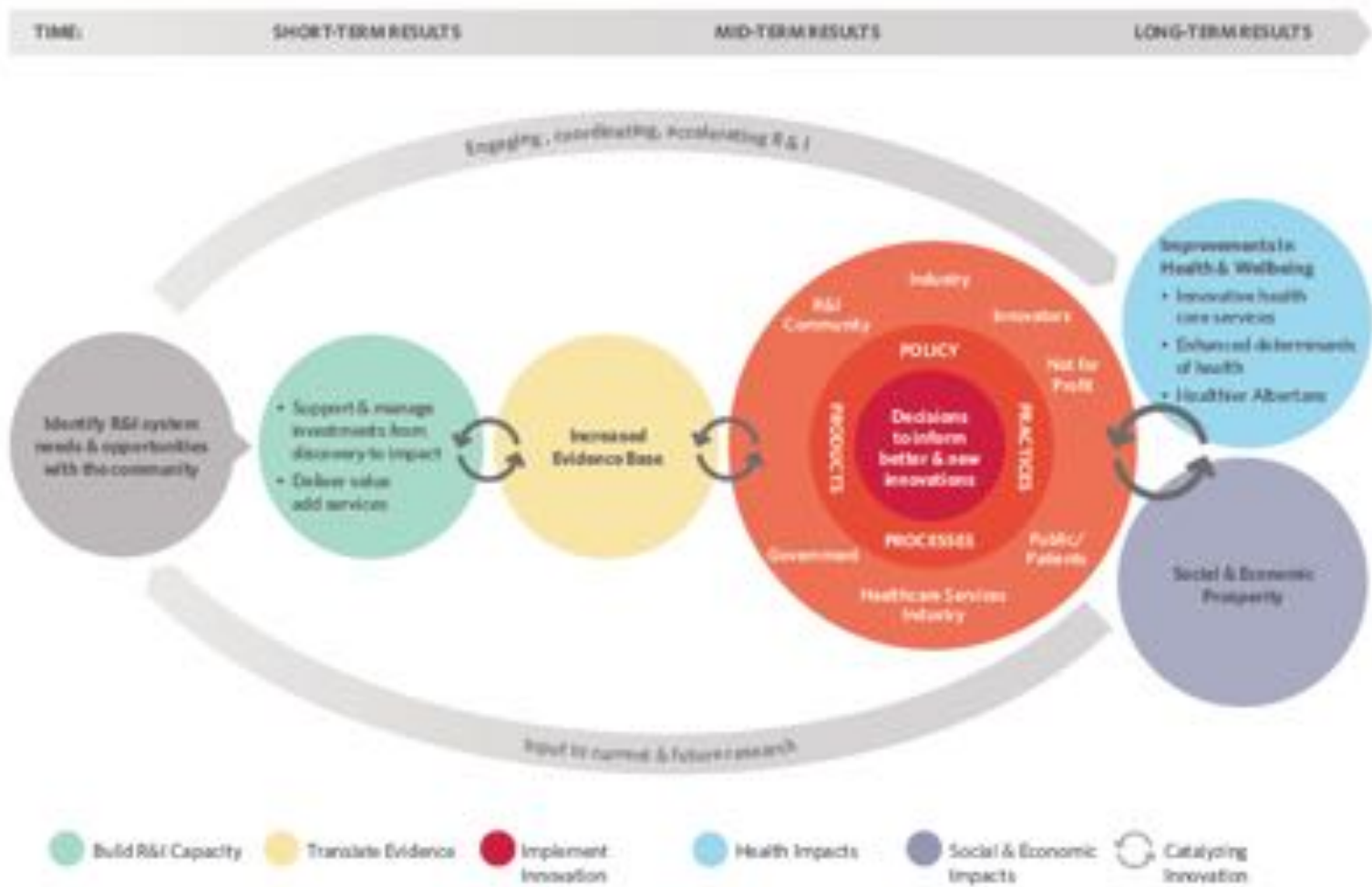
Summary of the Report on the Return on Investments in Health Research  
January 2009



<http://cahs-acss.ca/making-an-impact/>

*The Canadian community is taking a bottoms up approach to implementing impact – many alliances*

# AI'S IMPACT STRATEGY:



Performance Measurement, Evaluation and Assessment Activities

# USE A “FIT FOR PURPOSE” 6 BLOCK

1. Understand the context
2. Identify the assessment purpose
3. Define indicators of success
4. Develop the design, methods & data collection
5. Communicate and use findings
6. Manage the assessment



**The International School  
on Research Impact Assessment**

“Learning to assess research with  
the aim to optimise returns”

**ISRIA developed an  
impact assessment  
plan (strategy) using  
the 6 block protocol**

**Alberta continues to deliver regional  
training courses on Research Impact  
Assessment**

# National Institute for Health Research (NIHR)



*National Institute for  
Health Research*

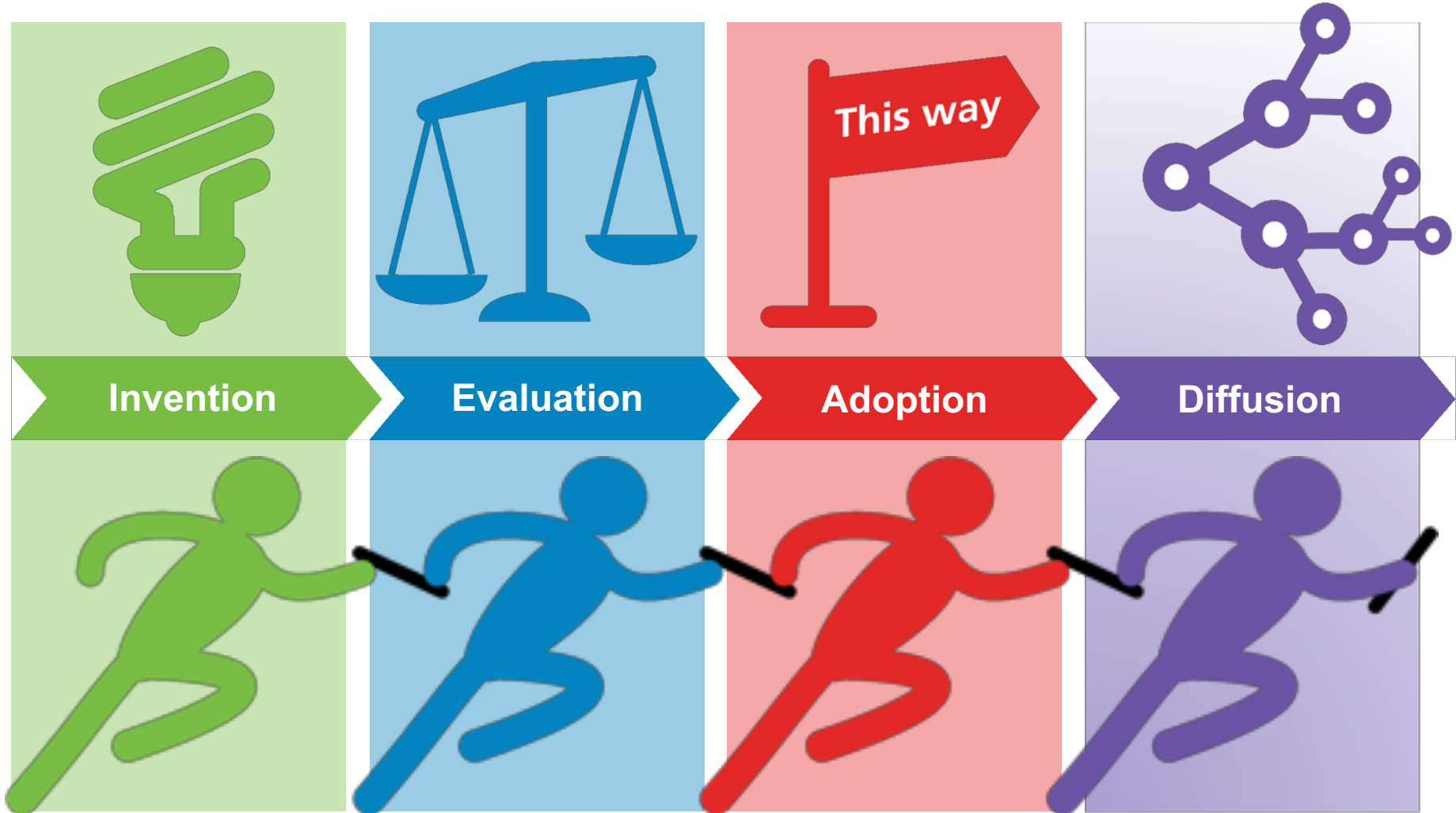
- Aim: Improve the health and wealth of the Nation
- Public funder overseen by the UK's Department of Health and Social Care
- Health, public health and social care
- Integrated research system
  - Infrastructure and support
  - Training
  - Research delivery
- Support translational research, addressing gaps in the translational pathway

# Our Impact Approach

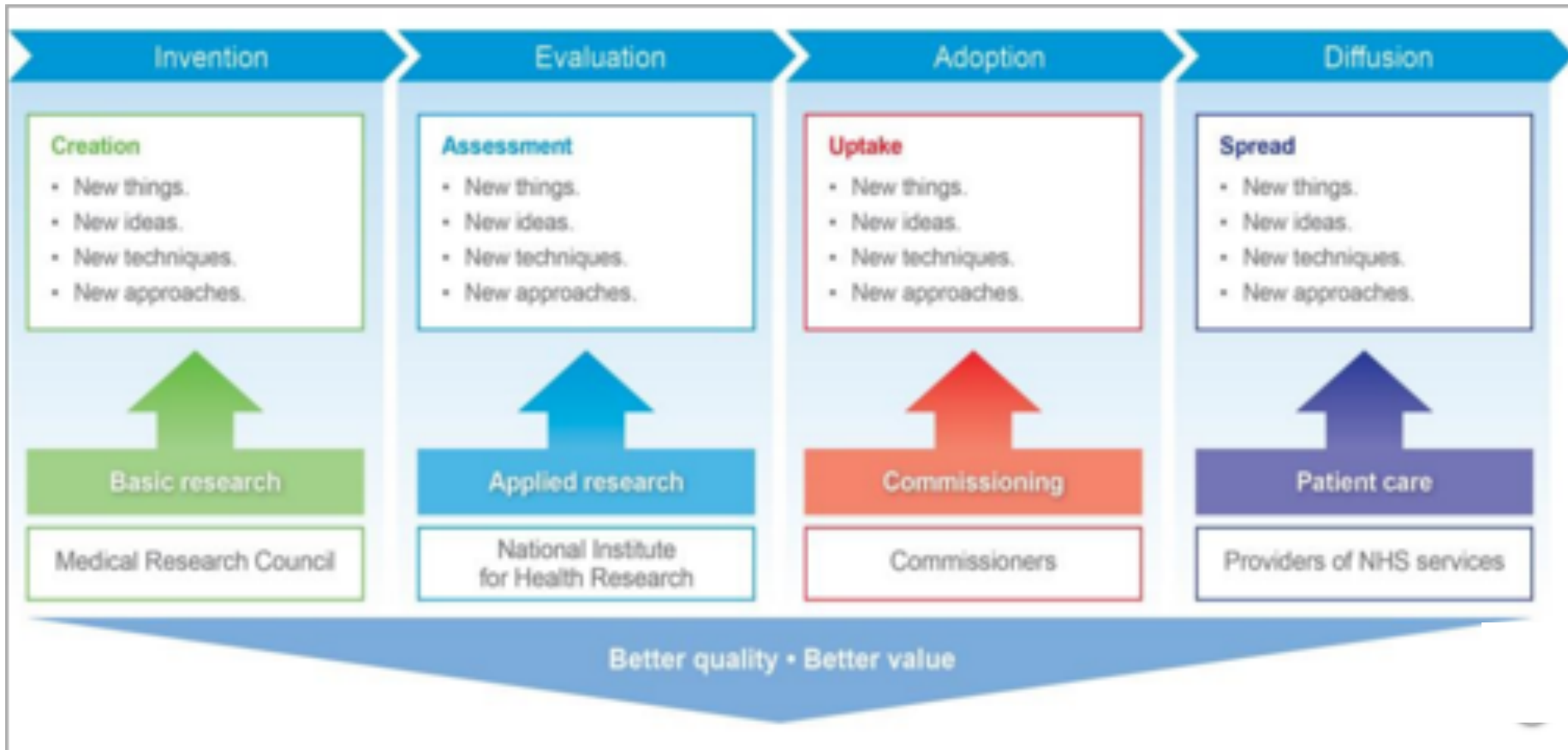


- NIHR-wide approach is currently in development
- Pockets of good practice
- Underpinned by basic logic modelling
  - What is the purpose of the funding?
  - How was it expected to work?
  - What has happened?
  - What has been produced?
- Development of 'value framework'
- Data audit currently underway
- Focus on our contribution rather than attribution
- Recognising the cultural and behavioural challenge as well as the practical

# The Research Pathway



# The Research Pathway





# Novo Nordisk Foundation (NNF) Independent Foundation with Corporate Interests



novonordisk  
fonden

Dividende

novoholdings  
Investors in life science

Dividende

75% VOTES

70.9% VOTES



## Grant-awarding

**New grants in 2017:**  
DKK 5.2 bn  
(EUR 0.7 bn)

Scientific research  
Diabetes treatment  
Innovation  
Education and outreach  
Humanitarian and social purpose

## Investments

**Net profits in 2017:**  
DKK 19.1 bn  
(EUR 2.6 bn)

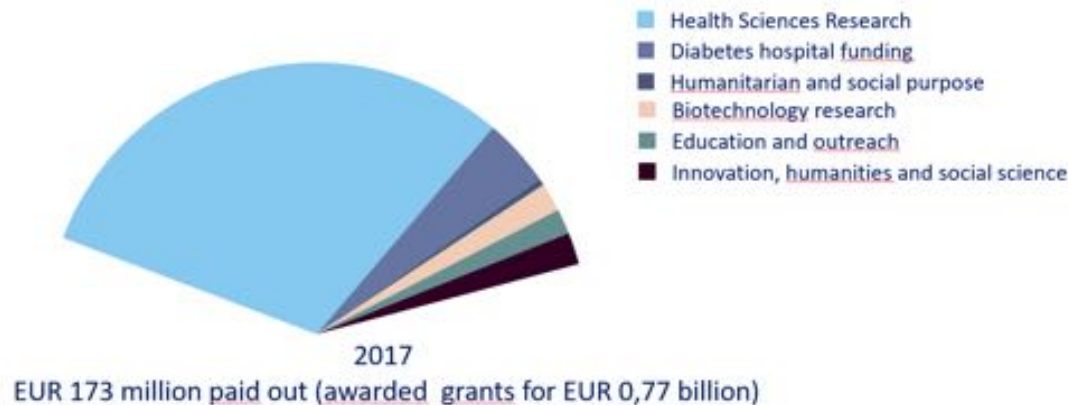
Principal investments  
Venture investments  
Seed investments  
Financial investments

Knowledge is the key

# Areas of Support and Purpose

## Areas of Support

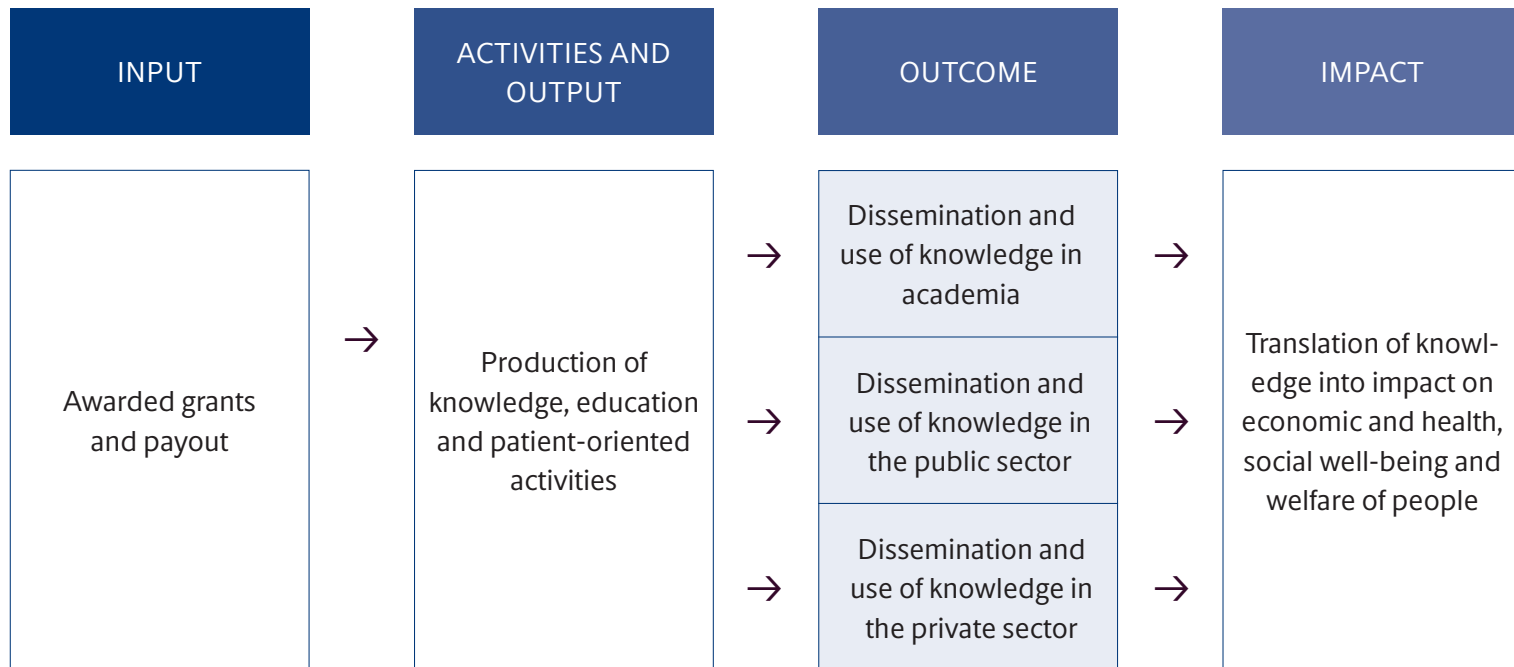
”...to improve the health and welfare of people.”



## Purpose of impact assessment

- Develop novel and research-based impact assessment, analysis of funding science and capacity building
- Document and measure the impact of public research in Denmark
- Develop, collect, process and analyze information on all activities the Foundation supports

# NNF Model





## 2. GLOBAL IMPACT STRATEGY

### PROOF OF CONCEPT EXPLORATIONS

# DATA INTEGRITY

## DATA CHECKING PROCESSES

2 Data integrity

Continue efforts in achieving data integrity and achieving high data quality

COMPLETNESS

ACCURACY

TIMING

*All organizations conduct quality data checks –  
Future opportunity to share integrity protocols*

# ANALYSIS EXPLORATIONS

3 Analytical capability and capacity

Develop opportunities for building capacity and capability to benefit from the potential in analysis

HARMONIZE  
FUNDING  
INVESTMENTS

IMPACT ANALYSIS  
EXPLORATIONS

SHARE PROMISING  
PRACTICES

*We have started to share practices with each other that we each would like to adopt*

# HARMONIZE FUNDING MECHANISMS



## RESEARCH AWARD (Including Intramural Programme)

The primary purpose of the award is to undertake research (e.g. projects, programmes etc.) of interconnected research. These awards typically support all the direct costs involved in conducting specific research projects performed by identified researchers. Operating grants typically cover salaries for laboratory staff and research assistants/associates/trainees, costs of research equipment and supplies, and other specific research-related expenses.

## CAPITAL/ INFRASTRUCTURE AWARDS

The primary purpose of the award is to support research infrastructure, provide capital and or equipment. These awards cover, in part or in full, the costs of construction or major remodelling of new research facilities, and/or the purchase, housing, and installation of equipment, scientific collections, computer software, information databases, and communication linkages used primarily for conducting research. It includes funding for costs associated with cohort establishment.

## FELLOWSHIPS AWARDS

The primary purpose of the award is to enhance and develop an existing research career. These awards provide protected time for research on either a long- or short-term basis to outstanding researchers who have demonstrated high levels of productivity and research accomplishments. These awards are given to only a small percentage of all researchers. (They may also be called salary awards.)

## STUDENTSHIP AWARDS

The primary purpose of the award is to kick start an interest in developing a research career. These awards recognize outstanding students and support them during their undergraduate and masters. Block training grants given to institutions that in turn distribute the monies to students through a competitive process are also included under this funding award type. These awards are in addition to trainee salaries covered in operating grants.

## TRAVEL/SMALL PERSONAL

The primary purpose of the award is to provide comparatively small amounts of financial support to support researchers and research. These awards support travel, workshops/symposia, and researcher time for proposal development/letters of intent.

Operating grant

Collaborative awards

Industry collaborations

Infrastructure, equipment and/ or maintenance

Research platforms

Salary award

Research chair

Doctorate

Post-  
Doctoral/Fellowship

Undergraduate/

Masters

Mentoring  
program

Knowledge

exchange/mobilization

Visiting Lecture

*Harmonization of award types and programs will help us characterize our investment strategies internationally*

# IMPACT ANALYSIS EXPLORATION

## Timeline

- 2015 to 2017

## Analytic Groupings

- 1: (Projects) 0-3 years,  
0 - €400.000
- 2: (Small programs) 3-5 years,  
€400.000 - €2.7M
- 3: (Large programs) 5-7 years  
€2.7 million - €8M
- Group 4: (Very large programs/ Research  
Centers) >5 years,  
€66,7 - €267 million.
- 5: Fellowships/post-docs

## Impact Results

- Publications
- Collaborations
- Promising practices

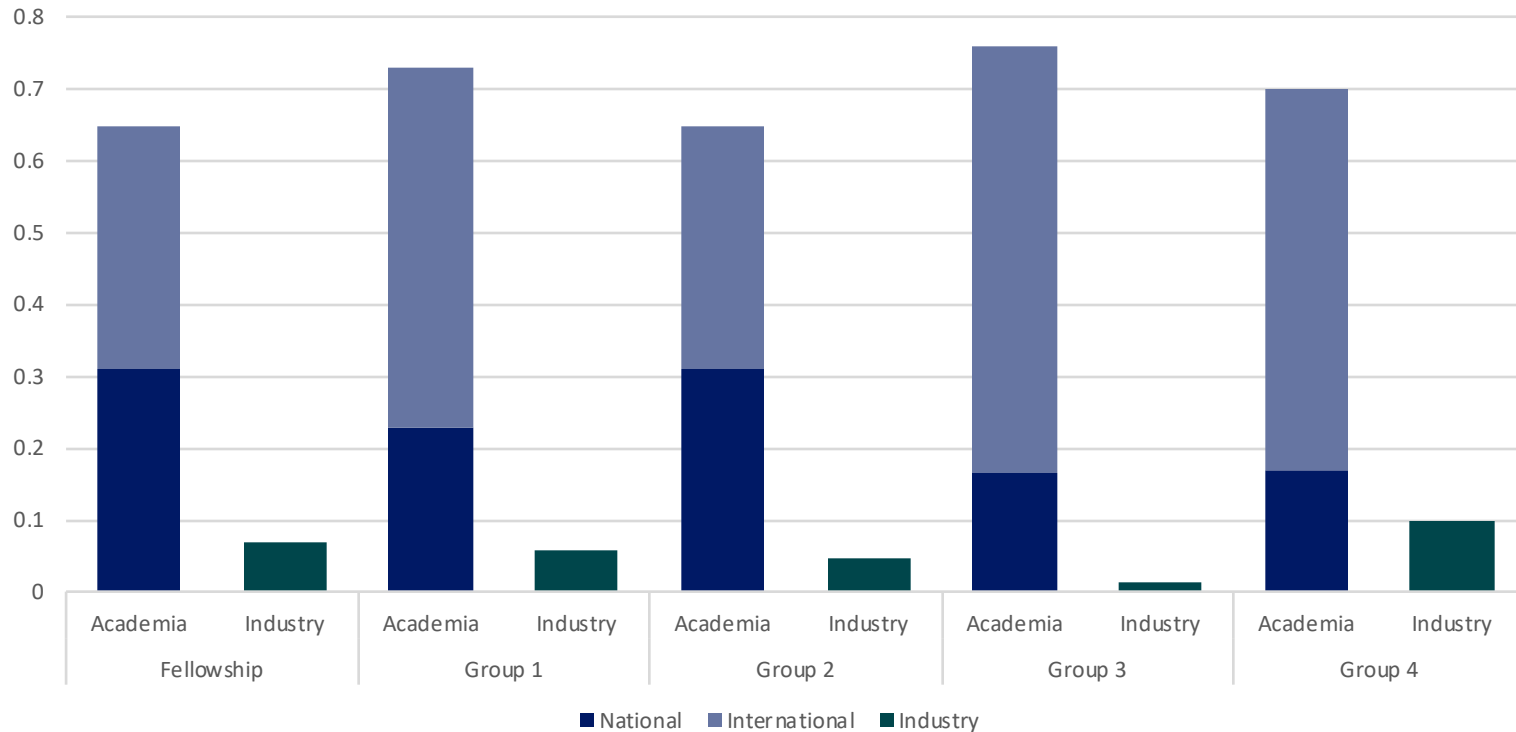


*All organizations report annually -  
future opportunity to harmonize and do deep dive analysis*



# NNF Promising Practice – Bibliometrics

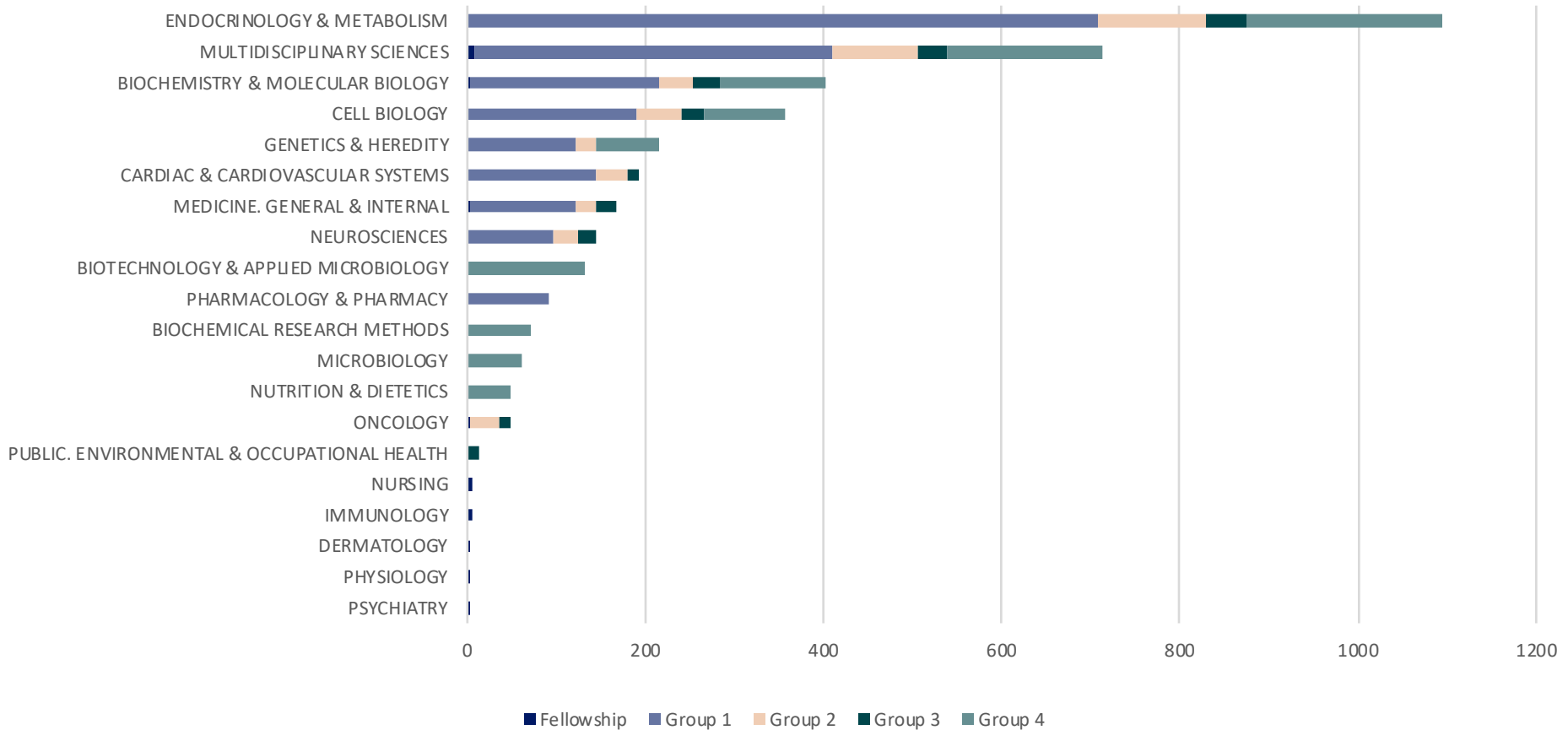
Share of journal articles by co-authorship, NNF



*We can start to do deep dive on co-authorship analytics*

# NNF Promising Practice – Bibliometrics

Co-authorships distributed on WoS subject categories, NNF

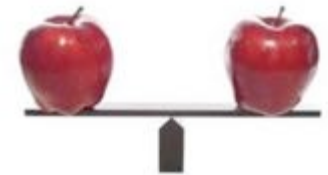


*We can start to do deep dive on subject categories*

# AI PROMISING PRACTICE – HARMONIZE BIBLIOMETRIC ANALYSIS IN CANADA



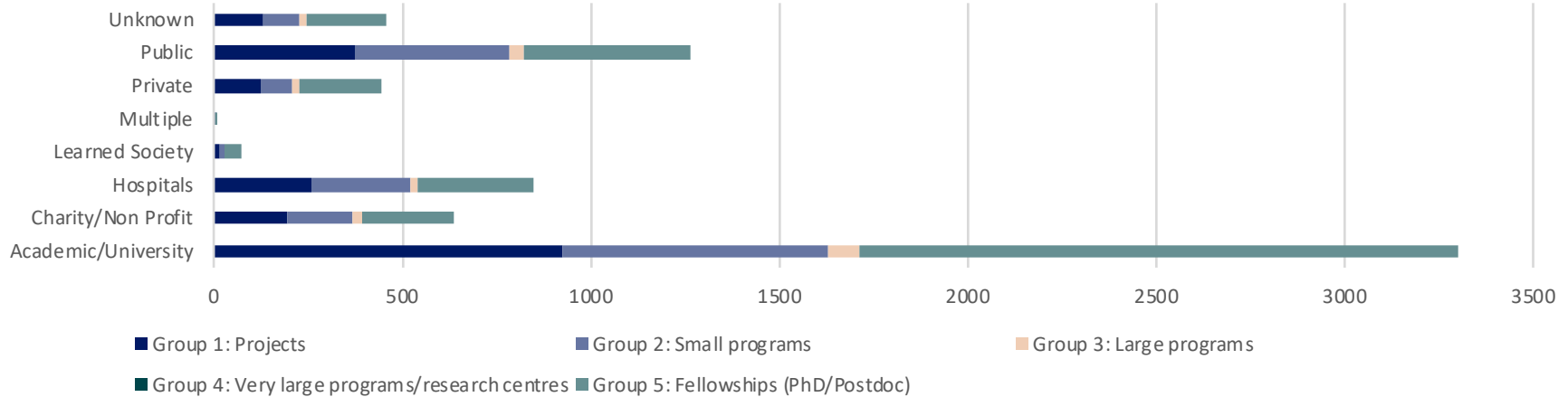
NAPRHO Indicator	CAHS Indicator
B5 Publications	• Share of Publications
B15 Publications in top journals	• Publications in high-quality outlets (or desired outlets)
B1 Life Science Specialization Index (SI)	• Relative activity index
B12 Comparative publication rates (CPR)	• Share of Publications • Field Citation Analysis
B3 Average Relative Citation (ARC)	• Relative Citation Impact
B6 Interprovincial collaboration rates	• Co-author analysis
B8 Interprovincial field comparisons	• Field Citation Analysis • Relative activity index
B9 International collaboration rate	• Co-author analysis
B11 Academic user collaboration rate	• Co-author analysis • Collaboration with Industry
<b>NAPHRO Added Indicators</b>	
B10 Publications by top 20 researchers	
B2 Average Relative Impact Factor (ARIF)	
B7 ARIF of interprovincial collaboration	
B13 International collaboration – top 10	



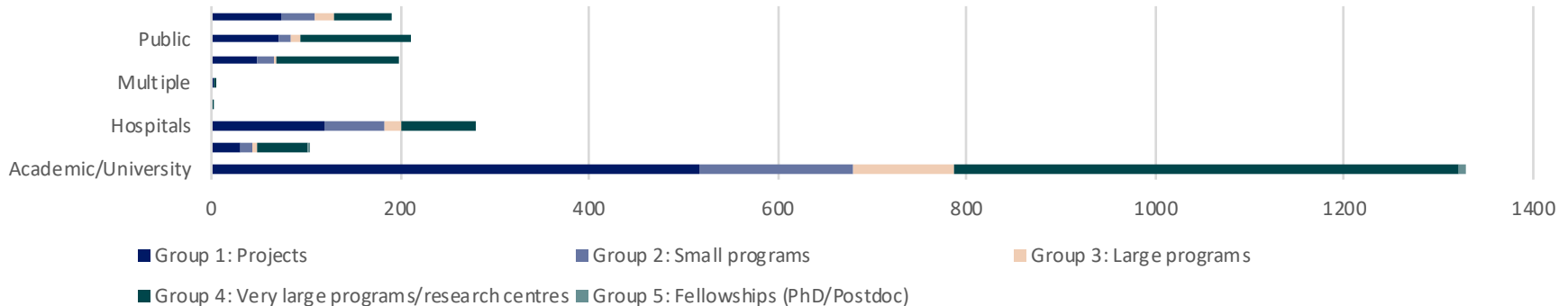
*Advancing Knowledge Impact is broken down by: Quality, Activity, Outreach, Contextual. Taxonomy can be used to structure analysis in the future.*

# Illustration Only - Collaborators Distributed by Sectors, NIHR, NNF

NIHR



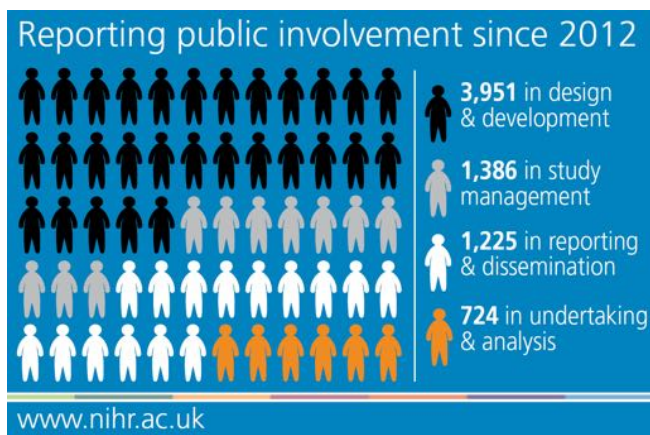
NNF



*We can start to analyze collaborators across sectors*

# NIHR PROMISING PRACTICE

## KEEPING PATIENTS AT THE HEART OF RESEARCH



- Sample PPI\* questions

Q1: Have you involved patients and/or members of the public in your research?

A1: \*Yes/No/\*\*Not applicable/Unknown

\*\*Q2 [Only for those answering Not applicable to Q1] Why was PPI not applicable in your research?

A2: [Free text]

\*Patient and Public Involvement

“Involving patients and the public is very important in helping address some of the most important challenges in healthcare. Using tools to document it further encourages researchers and funders to engage them by showing examples of how this involvement can help make their work even better. It will also encourage more patients and members of the public to get involved by showing them that it is an interesting and good use of their time and how their experiences can be used to help others. Data already captured on Researchfish shows a wide range of ways

\*If Q1 answered Yes.

Q3: How have patients and the public been actively involved in your research? (Please indicate all that apply)

A3:

1. Prioritising the research question(s)
2. Developing the application for funding
3. Design of the research
4. Management of the research
5. Undertaking the research

# AI PROMISING PRACTICE

## HEALTH TAXONOMY FROM CAHS

- Additional questions on six dimensions of health and sample indicators
- Taxonomy also used by Alberta's health system
- We are using to assess the scale up and spread of research evidence to impact



Acceptability	Accessibility	Appropriateness	Effectiveness	Efficiency	Safety
<ul style="list-style-type: none"><li>• Self-reported patient satisfaction</li></ul>	<ul style="list-style-type: none"><li>• Wait times</li><li>• Appointment statistics</li></ul>	<ul style="list-style-type: none"><li>• Adherence to clinical guidelines</li></ul>	<ul style="list-style-type: none"><li>• Re-admission rates</li></ul>	<ul style="list-style-type: none"><li>• Actual vs. expected</li><li>• Hospital stay</li><li>• Cost input versus output</li></ul>	<ul style="list-style-type: none"><li>• Adverse drug effects</li><li>• Hospital acquired infections</li></ul>

# BETTER COMMUNICATE - IMPACT NARRATIVES



novo nordisk fonden

### Collaborating from 'Door to Needle' to Implement New Stroke Therapy



A team of researchers led by Dr. Michael Hill is using an endovascular treatment (ET) to improve the quality of stroke care. Stroke patients receive ET treatment during transport on specialized ambulances to improve health outcomes. This is integrated health service delivery in action.

**Researchers:** U of C (2017 Team and Collaborators)

**Subjects:** Stroke patients combined in-person and remote experience

**University of Calgary:** Clinical Research Unit (CRU) led by and the Calgary Stroke Program and Stroke Centre (SCPC) staff

**Acute Care (non-stroke):** Nurses, Endocrinology, Stroke Pharmacology, and Emergency Physicians

**Peer Organizations:** Advancements and medical tools, SAAS/IC (General phone services, STARS (air transport))

**Emergency Departments:** Advancements and medical tools

**Strategic Clinical Networks (SCN):** Advancements and medical tools (all services, Emergency SCN, Cardio, Health and Stroke SCN)

**HEALTH IMPACTS**

Early treatment of stroke will improve recovery outcomes for patients and reduce death from strokes. This new therapy is available in rural areas, potentially reaching 25% of stroke patients.

"The overall mortality rate was reduced from two in 10 patients for standard treatment of care to one in 10 patients - a 50% cost reduction with 50%." (2018 Stroke Canada, Feb. 11, 2018)

**SOCIAL AND ECONOMIC IMPACTS**

"This novel stroke care model from a remote stroke to a new stroke, you save the health system a million dollars in lifetime costs, and you save the patient years having a fit of another and helps them back to their life."

-Dr. Tom Avaris (2018 Stroke Canada article, July 9, 2018)

The team brought \$4 million in funding to support their work.

### Classification and prognostification of colorectal cancer

Colorectal cancer is known to have great inter-tumour diversity which means that the cells in the tumors can be very different. Tumours at the same stage can equally be very diverse and unpredictable. Due to this great diversity in colorectal cancer prognosis and response to treatment can be difficult to predict leading to both under- and overtreatment.

The research group under Jesper Bertram Bramsen has found a molecular-subtype-specific biomarker that can be used to improve the prognosis for patients with colorectal cancer. The research group has analysed 1,100 colorectal cancer samples, discovered three different cancer cells and five tumour archetypes and made it possible to find specific subtype-biomarkers. This subtyping-framework and the newly discovered biomarkers can be an important factor in improving the treatment and prognostics for colorectal patients.



**The beautiful game**

**The challenge**

Colorectal cancer is a leading cause of cancer death and disability in the world. The challenge is to find better ways to diagnose and treat the disease. The research group under Jesper Bertram Bramsen has found a molecular-subtype-specific biomarker that can be used to improve the prognosis for patients with colorectal cancer. The research group has analysed 1,100 colorectal cancer samples, discovered three different cancer cells and five tumour archetypes and made it possible to find specific subtype-biomarkers. This subtyping-framework and the newly discovered biomarkers can be an important factor in improving the treatment and prognostics for colorectal patients.

paths of colorectal cancer. The findings are published in a new subtypes-framework.

*We all use impact narratives – Future opportunity share templates and products*

# FUTURE DIRECTIONS



## ALBERTA INNOVATES

- Ex-ante focus - impact planning
- Schedule follow up analysis
- Assessing scale up and spread
- Apply across sectors

## NIHR

- Build data collection into business as usual
- Develop value framework

## NOVO NORDISK FOUNDATION

- Ex-ante focus
- Impact assessment on patient oriented initiatives, educational grants and humanitarian and social grants
- Follow up analysis on industry collaboration

We need new ways of working to move collaborations forward and new governance mechanisms for connecting and sharing data. We will continue to work on expanding the “elements” and proof of concept as a means of understanding “what works, does not work, under what conditions”.





# REFLECTIONS ON INCREASING THE USE OF IMPACT DATA

# TRACKING IMPACT ACROSS THE RESEARCH CYCLE

4 Data connectivity within research ecosystem

Explore further potential in connectivity with other parts of research ecosystem

Pre Grant

Grant Period

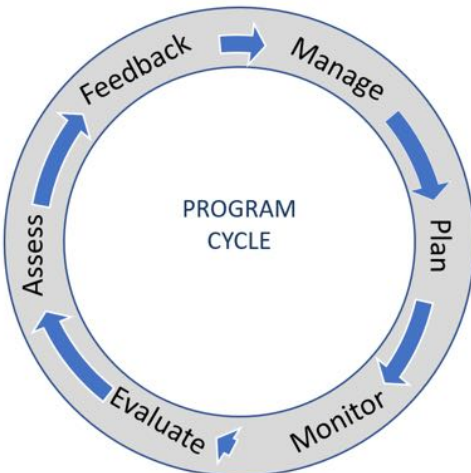
End of Grant

Post Grant

Internal Data Sources

External Data Source

Researchfish



# LESSONS LEARNED

- Need a collaborative **protocol** for sharing, querying analyzing data
  - Establish principles
  - Identify assessment questions to drive meaningful analysis
- Adopt **international** standards, guidelines, and taxonomies to make more use of the data
- **Add a fifth element** – application and sharing of leading and promising practices in health (aka international alliance) and across sectors
- Having theme working groups helps increase use:
  - Public and patients
  - Impact narratives



Need a safe place to test ideas – a safe to fail  
Innovations such as Implementation labs

# THANK YOU



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