

Response from
the Irish Cancer Society
to consultation paper for
Successor to
Strategy for Science, Technology and Innovation.



Executive Summary

Founded over 50 years ago, the Irish Cancer Society initially developed as an advocacy group for patients and their families. In subsequent decades we have taken on a larger role of funding and advocating for research in this field. To that end, we have invested over €30M in cancer research and funded in excess of 200 cancer research projects.

We welcome the government's strong commitment to science, technology and innovation as articulated in the previous STI strategy and the firm commitment to resource this area into the future through the development of a successor strategy.

With a large predicted increase in many health disorders, including cancer, in the coming decades we wish to bring attention to a number of practical challenges impacting research, especially biomedical research, and make recommendations which might drive this plan for the benefit of our community (researchers, economic growth and, especially, patients).

These recommendations can be broadly encapsulated as follows:

- 1) Research must become "hardwired" into the healthcare system. This is a very economical driver of improvements in quality and delivery and will allow us to overcome impending national healthcare challenges.
- 2) A refocus on research sustainability and the longer term needs of our nation. In particular, an investment in sustaining human capital to derive a better return on our research investment.
- 3) Removal of well recognised barriers to investment and research operations. There is significant opportunity to make small but very impactful changes in aspects such as taxation and governance/oversight of research conduct which could rapidly have very positive effects on the operations and scale of activity in this sector.

Introduction

The Irish Cancer Society is the leading voluntary funder of cancer research in Ireland. Because of our unique position of independence we occupy a position of high credibility, honour and respect among the research community in the republic of Ireland. Since 1963 the Society has invested more than €30 million in cancer research. It has funded over 200 research projects in the Republic of Ireland and this has led to significant improvements in our understanding of the mechanisms of the development of cancer and to better therapeutic strategies & outcomes for cancer patients. Our research funding has helped to establish the Irish Clinical Oncology Research Group (ICORG) which has allowed thousands of patients to avail of new treatments in therapeutic trials.

We believe that the quality of cancer care available in Ireland depends on the quality of cancer research taking place here. This close relationship between research and clinical activity is an important way of raising the standard of both and we work closely with the other state funding institutions such as the Health Research Board and Science Foundation Ireland to this end.

In our Strategic Statement 'Towards a future without cancer 2013-2017', we have set out ambitious and far-reaching objectives to fund excellent collaborative cancer research. Our aim is work with partners to fund sustainably, collaborative cancer research model so that people who get cancer in Ireland will have better access to improvements in the diagnosis and treatment of their condition; this will lead to better medical care, better use of resources and improved outcomes.

The number of cancers diagnosed in Ireland is rising with an expected doubling of invasive cancer diagnosis to 60,000 per annum by 2040. The number of people surviving cancer is also rising- almost 60% of patients treated today will live for 5 years or longer post-diagnosis. But cancer is not the only challenge our health system faces; the incidence of all other chronic diseases is rising alongside increasing health problems such as diabetes and obesity. We believe that research has a major role to play in combatting these national challenges.

Research must become hard wired into the healthcare system

Irish researchers are continuously discovering ways to improve patient outcomes through the development of new drugs and treatments. The healthcare system is also benefitting from the high standard of research and this is reflected in improved quality, patient engagement, staff morale, the status of our research institutions and economic return on investment in R&D.

However, the limited amount of structural and institutional support for conducting research means that Ireland is at a competitive disadvantage to other more supportive jurisdictions such as the Nordic nations. This limits Ireland's ability to market itself internationally as an attractive research location and could lead to the flight of the world's best researchers to more advanced territories. The Irish Cancer Society believes that research needs to become a critical component of the health system and needs to be considered as fundamental to patient outcomes as healthcare itself.

In order to achieve the vision we have for research in Ireland, the Society makes the following recommendations:

Key requirements

- 1. We urge a move towards a complete integration of research into the fabric of healthcare delivery;**
- 2. It is essential to prioritise health research;**
- 3. While we welcome the appointment of a Chief Academic Officer with all new hospital groups, research should be embedded in the health sector (with a specific Director of Research) and build an ethos in healthcare that research is crucial to normal operation;**
- 4. A National Institute of Research should be developed such as the NIMR in the UK, building on and integrating with existing research infrastructure such as ICORG and HRB funded clinical research facilities;**
- 5. Ideally, research would be incorporated into all aspects of healthcare services but there needs to be a strategy to prioritise research in critical areas and conduct research efficiently with high impact;**
- 6. We need to better highlight and communicate the benefits and outputs of an enquiring system for all stakeholders and the public;**
- 7. Patient data needs to be tracked and monitored more effectively and the roll out of the key enabling IT technologies which would underpin such a development needs to be accelerated (electronic patient records, for example).**
- 8. Research careers need to be actively supported in the healthcare system and institutions need to make appropriate personnel commitments in terms of statutory pension contributions and be given flexibility to make staff appointments in areas of key need and demand, independent of moratoria which exist in the system as a whole.**

A refocus on research sustainability and the longer term needs of our nation.

As cited in the Successor Draft consultation document, while there is no question that there has been an enormous percentage increase in national spending on research in Ireland in the last 40 years, it is still clear that Ireland lags well behind the European average for per capita commitment for this vital area.

In the harsh economic climate that has existed for the past 7 years, there has been a clear need to prioritise scarce research investment resources on high impact, short term return, such as jobs and commercial development. When different research sectors are compared, it is clear that biomedical research areas typically do not deliver the same short term return in terms of jobs and direct economics and this has been used to justify significant reductions in the proportion of the research budget allocation dedicated to biomedical and basic research areas.

International experience unequivocally indicates that a properly balanced portfolio of investment in short, medium and long term forms of research, including adequate provision for basic and biomedical research areas, is key to the longer term economics, sustainability and health of a nation. Such a balance in the portfolio reduces reliance on single areas which, over decades fall into decline, and allows our nation to be best placed as new research areas become dominant economic drivers.

Much of the national research investment has been focused on evolution of a complex web of infrastructure and equipment which is, of course, generally, extremely important in high tech R&D. However, it is recognised that in all sectors of research and enterprise, human capital is far more important and a much greater driver of innovation and economic return. Human capital elements appear in a number of areas in the consultation document but we think the deficits recognised need clear action to bring about the change required. While substantial investment has also gone into education and generation of a large portion of postgraduate and postdoctoral researchers, there is no sustainable model for the longer term anchoring of such extremely expensive human capital into sustainable enterprise models. Despite the cost of such training many of our most skilled and engaged graduates are ultimately forced out of the areas where their expertise lies and/or emigrate permanently out of our system.

Much of the investment being made in high tech equipment and resources is being simply wasted over time as there is no longer term sustainability model which supports service, maintenance and upgrade of such equipment into the future, nor a proper allocation for maintaining the level of expertise needed to keep such resource operating well into the future.

There is no doubt that Irish research output has punched above its weight, for example, investments in basic immunology, animal & dairy, nanotechnology and computer research have led to a pre-eminent scientific standing in these fields. There is also no question that there is a significant bias towards publication output as a measure of success and it can be hard for the lay population and industry to see where the return will be in such investments. Notwithstanding that, there needs to be a significant level of basic and curiosity-driven research conducted in Ireland, where research is meant to be more applied, we need to see greater partnership between industry and patients groups in research to help keep a focus on practical and useful outcomes.

Key requirements

- 1. We urge a better engagement with recognised experts across the many platforms of science, engineering and research to strike a more sustainable long term research balance which encompasses the spectrum of needs of the Irish community across all areas and over longer terms and is not purely driven by short term economic return, i.e. a re-balance of basic and applied research;**
- 2. We propose a national focus on improved sustainability for research which integrates infrastructural and personnel aspects;**
- 3. Establishment of an interdepartmental government committee to oversee larger scale infrastructural investment and ensure that such investments are made into national centres of expertise and duplication is avoided;**
- 4. Bring together stakeholders in Education, Science and Innovation to develop a proper model of sustainable career evolution for research, which focuses less on number and more on quality outcomes and personnel retention, for example partnering with academic institutions to evolve a 4th career path based largely on research (in addition to the existing paths in academia, administration and technical aspects);**
- 5. Infrastructural funding models which focus less on short term projects and more on longer term >5 year support, with commitment for longer term sustainable funding to maintain these resources in a current and viable manner long into the future (with appropriate oversight to ensure ongoing delivery of required milestones);**
- 6. In biomedical research, relevant patients groups should be included in the oversight boards of key strategic initiatives as a matter of course;**
- 7. Research needs to be seen as a default right of patients not something that is irrelevant to the majority of their involvement with the health system;**
- 8. Industry representatives need to be encouraged to take a more active role in steering the research agenda;**
- 9. There needs to be provision for better communication of research and its delivery so the population can see the impact of their investment . This will also encourage young people to look to this sector for lifelong careers. A national research communications office needs to be established under the auspices of an existing state agency, such as the Health Research Board or SFI;**
- 10. Irish researchers have successfully secured major national and international funding investment but we need to examine the potential of cross-leveraging research funding and drawing together national, international, industry and charity funding in a more integrated manner. This should focus on the needs of the population and generating a more sustainable scale of joint investment;**
- 11. The overhead payment model for research needs to be re-examined to incentivise institutions to properly invest in and commit to research. In particular, the higher education sector needs a greater overhead provided for the conduct of research, more in line with international norms, moving away from cross funding from the student education "pot".**

Barriers to investment and operation of research urgently need to be removed

There are a number of very significant log-jams for institutions, NGOs and industry involvement in biomedical research which could be relatively easily removed if appropriate action was taken. The 2004 Clinical Trials Act and related legislation created an operational framework for interventional studies in medicine, however follow up legislation to provide a similar framework for non-interventional and translational studies is now long overdue.

Much of the framework for such activities is covered in the Health Information Bill but this legislation has now been delayed for more than 5 years. The consequence of this legislative deficit is that multi-institutional, non-clinical trial, biomedical research has an unmanageable burden of ethical oversight from a significant number of ethics committees. This is creating a situation where it is next to impossible to conduct even the simplest studies, for example routine questionnaires, in a timely and efficient manner because of the large amount of additional bureaucracy and oversight from multiple ethics committees each often with differencing views on aspects such as consent and language.

Ethics committees themselves appear to be grossly over stretched and under resourced for the roles they are being required to undertake and currently there is no real oversight for the many ethics committees dotted around the country.

Inappropriate taxation is also a significant impediment to investment. At the moment, roughly 23% of infrastructural and consumable spend is lost straight back into the taxation system. Taxation on research spending is particularly difficult to bear for the charity sector which endeavours to fund research. Abolition or reduction of the tax burden in the area would allow research investments to go much further.

The application of data protection legislation in the healthcare setting has also begun to directly impinge upon the ability to conduct high quality research, further impinging our ability to derive community benefit from healthcare findings.

Key requirements

- 1. The Health Information Bill must be moved to legislation as a matter of extreme urgency;**
- 2. There needs to be an oversight body for all Ethics Committees to ensure standardisation and such committees need to be adequately resourced to undertake the demands being made upon them;**
- 3. HIQA has been proposed as an oversight organisation and if this is the chosen approach, then this body needs to be mandated and resourced to rationalise and improve quality in this sector;**
- 4. There needs to be full standardisation of operational documentation for researchers taking patient material and information, to ensure consistency across the sector;**
- 5. We also need to see investment in a national infrastructure for biobanking and a body which will oversee licensing and regulation of practical aspects of sample procurement and storage in a standard and internationally harmonised manner as happens in many other European countries;**

- 6. The proposed unique patient identifier system needs to be urgently operationalised so that individuals can be tracked through the healthcare system throughout their lives for research purposes;**
- 7. We urge an improved communication between healthcare providers and the Data Protection Commissioner to make for a safe but operationally streamlined process for capture, retention and analysis of personal and systemic healthcare data;**
- 8. Taxation reform in the sector is badly needed and taxation on academic expenditure in research should be abolished or reduced, as has been done in the hospitality sector;**
- 9. Currently the charity sector cannot recoup any intellectual property return on their investments because their investments are subject to VAT. The taxation system should be reformed to allow charities to recover any “rewards” for their investment without being subject to such direct taxation, thereby allowing and encouraging them to reinvest any returns they may receive. For example, the Irish Cancer Society has invested approx. €30m in research but not been able to recoup any return for this investment.**

Conclusion:

Tremendous progress has been made through the focus and structure of the previous SSTI, particularly against the backdrop of harsh economic realities. To build on this progress, we propose a focus on three key areas:

- Better integration of research into our healthcare delivery model
- A renewed focus on longer term research sustainability
- Removal of key barriers which currently impede the organic growth of this sector.