

Introduction

This submission was written in response to the Interdepartmental Committee on Science, Technology and Innovation consultation paper for the successor to the Strategy for Science, Technology and Innovation. In the context of selected 'Pillars' (as per the Consultation document) this submission reflects IPPOSI's (Irish Platform for Patient Organisations, Science and Industry) well-established patient-centred perspective in medicines, treatments and policy development.

Pillar 1

- **1.1: What should Ireland's ambition be in STI?**

IPPOSI believes research planning and strategy demands a wider context than jobs alone, because of the wider societal benefits research provides. Research does not only add to society through jobs and economic activity, but through new treatments and new care pathways for patients. IPPOSI also wishes to emphasise that public support for research, and access to research is strong, as evidenced by our own research into public attitudes undertaken in 2009¹. This work found that:

- 70% of Irish people agreed that they would be willing to donate their blood for clinical research (18% disagreed)
- 65% agreed they would be willing to supply personal medical information for medical research provided their information was kept confidential (19% disagreed)
- Furthermore, 77% agreed that carrying out clinical research in Ireland with a view to developing new ways to treat diseases is a good idea (8% disagreed)

This willingness to be involved in research points to what IPPOSI believes should be one of Ireland's chief ambitions in STI: Public Engagement. The research community and its stakeholders agree that it is important to inform the public about the value and contribution of research – and that this is an area where science does not perform well. The sheer breadth of what 'public engagement' could mean contributes to this problem, as 'public engagement' could refer to community-based, or schools-based initiatives, or it could mean a fully integrated marketing campaign.

Defining the meaning and extent of 'public engagement' will simplify the task of identifying what actions are most appropriate, but if we may assume the need for even the most basic level of public engagement, Ireland does not have to invent a model. We can take our lead from the UK, where researchers must satisfy a public engagement condition in order to receive funding. UK scientists are supported in this regard by INVOLVE and this is a model we could adopt in Ireland by providing our researchers with support to engage with the public through lectures, open days, school visits and so on, and that such provisions would be a requirement for grant recipients.

Key Irish universities have within their criteria for promotion for senior academic posts a requirement to fulfil 'civic and public engagement' activities. This encourages our academic scientists to engage with communities, patients and the general public within their chosen field of expertise. This model could be expanded to all universities throughout Ireland to encourage and reward public engagement type activities.

As our own research found, there is a public appetite to know more about research, and there are clear benefits to researchers and scientists when patients and the public know what they are doing

and why – what we must do is provide the simple structures, which already exist elsewhere, to make this possible, and this must be an ambition for STI in this country.

Pillar 2

- **2.2: How best do we identify emerging opportunity and challenge i.e. horizon scanning?**

The strands of research – basic, applied/translational, and clinical – should be working together, not competing, and we need to acknowledge that funding needs to go across the R&D ladder. Currently funding available is heavily weighted towards research with immediate commercialisation potential, and a recalibration is required. Future-oriented methodologies and techniques can be used individually or in combination, inside or outside scenario development. Horizon scanning is often based on desk research, helping to develop the big picture behind the issues to be examined. A solid 'scan of the horizon' can provide the background to develop strategies for anticipating future developments and thereby gain lead time. It can also be a way to assess trends to feed into a scenario development process. However, emerging opportunities are best identified by not limiting researchers to one technique. For example, methods such as the Delphi method and Trend Impact Analyses also warrants consideration.

Pillar 5

- **5.1: What could we do to further enhance our landscape and institutional arrangements to maximise the impact of research excellence and deliver jobs?**

Basic Research is the only way of generating new knowledge. This is a challenge for the new SST&I strategy in light of the government's focus on the jobs imperative, but the government must recognise that Basic Research – and subsequent innovation – is what attracts industry, and by extension jobs. Much of today's translational / applied / clinical research is carried out in-house by pharmaceutical companies. Funding Basic Research is essential if we want to maximise the impact of research excellence and deliver jobs, and we must recognise that Basic Research has the potential to create new and unforeseeable economic and job opportunities. For example, the diabetes treatment Insulin was developed following a Basic Research breakthrough in an unrelated field. Funding should not be either / or across the research ladder – the areas are interlinked.

Pillar 7

- **7.3: How can we address national challenges and also provide economic opportunities through the development of new products, processes, systems?**

Ireland should move quickly to support existing researchers (and attract new researchers and industry) by putting in place the necessary structures, including, but not limited to:

- The enactment of the Health Information Bill, and implementation of the Unique Patient Identifiers Act.
- Provide central support for establishing patient registries which in turn help to anchor industry, which in turn provide opportunities for patients to avail of the latest treatments via clinical trials. It is an undisputed fact that patient registries can be regarded as an integral part of a modern healthcare system with an established role in surveillance, health service delivery, research, patient care, Health Technology Assessment and for international reporting. While other information systems exist within the health services, patient registries if resourced and governed properly could play a very important role as a trusted third party that could:
 - Compile data,
 - Link/match data, as a trusted third party. A role that is informally carried out by the CSO without the allocation of resources,

- Interrogate and audit health data in the same way as a professional accounting firm would analyse and audit financial information.

The importance and need for high quality health information in improving the safety and quality of patient care has been outlined in a number of key national strategy documents from the Department of Health, including *Quality and Fairness – A Health System for You*, *the National Health Information Strategy*, and in the *Report of the Commission on Patient Safety and Quality Assurance – Building a Culture of Safety*. In addition the *e-Health Strategy for Ireland* (December 2013) highlights the importance of access to quality health data sources to drive improvements in the quality and safety of care.

The establishment of an independent “trusted third party” / Irish Registry Foundation could meet the challenge of maintaining quality repositories of clinical patient data in Ireland, initially for multiple chronic and rare diseases, but could include any disease. There is an increasing international trend to use patient registries to support part of pharmacovigilance and the audit of longitudinal patient outcomes. Patient registries are seen as an ideal trusted source of analysed de-identified data that can be outsourced by pharma as a paid for service.

- Innovate solutions in the area of Data Protection
- Introducing electronic care records for patients.

Pillar 8

- **8.2: What additional steps can government take to ensure the development of human capital across the population to ensure the success of the new strategy?**

Ireland needs to establish career paths for researchers so that our best and brightest have the opportunity to stay in Ireland, or attracted home after gaining international experience. Instead we need to build a strong reputation and culture in Ireland that attracts the best and the brightest to stay here, and indeed come here from other countries. Furthermore, we need to enhance the research environment for clinicians and researchers who are in Ireland, with one possible step being the introduction of protected time for HSE clinical staff, and following on from that, by making research targets part of their performance review. A dearth of researchers trained in high level epidemiology skills and data analyses techniques are hampering Ireland's ability to conduct research that has global consequences for population health.

References:

1. “Report into the General Public’s Attitudes towards Clinical Research”, Drury Research, on behalf of IPPOSI, 2009: <http://www.ipposi.ie/index.php/docman/reports/41-general-public-s-views-on-clinical-research/file>