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IPPOSI Submission to the Oireachtas committee on the Future of Healthcare

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IPPOSI Board of Directors

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Executive Summary

It is clear to IPPOSI members that the whole-system challenges that exist in the Irish health and social care system require fresh, long-range thinking combined with long-term, cross-party political commitment. There is also a clear need to establish a universal single tier service where patients are treated on the basis of health need rather than on ability to pay. The Committee therefore has the unique opportunity to establish a long-term vision on how the health and social care system can work best for those that need it most.

Members of this Committee are to define a clear 10-year strategy based on a concrete vision of what needs to be achieved by 2026. This vision needs to be based on an agreed outcome which will give IPPOSI members a target for where this journey is leading us and what citizen and patient benefits will arise. Setting targets presents both financial and political challenges but this cross-party Committee is well placed to hold tough on such targets.

Through an internal consultation process, members of IPPOSI have identified a number of key areas which, if properly supported, will enable a paradigm shift in the long-term planning for the future of healthcare in Ireland. These include:

1. Person-centered, coordinated care
2. Integrated sharing of Health and Patient Data
3. Rare Diseases and Chronic Diseases
4. Primacy of clinical research
5. Access to Health Innovation
6. National framework for scaling up of healthcare innovations
7. Primary care and front-line staff

At the end of this submission, IPPOSI offers views on the health service funding model which would be best suited to Ireland, as well as eight specific recommendations to Government or other actors which the Committee should consider in its report.

Main Submission

1. Person-centered, coordinated care

The policy narrative around the future direction and ambition of the Health and Social Care system needs to fully embrace the concept of people as partners in their own health and wellbeing and to firmly place *person-centered, coordinated care*¹ very firmly at the heart of future strategies and engagement. Policies should be based on the principles of patient empowerment, shared decision making, self-management support, care planning and goal setting as well as listening and patient narratives.

¹ Redding D, (2013) "The narrative for person-centred coordinated care", Journal of Integrated Care, Vol. 21 Iss: 6, pp.315 – 325 <http://www.emeraldinsight.com/doi/abs/10.1108/JICA-06-2013-0018>

Understanding “what matters to you” instead of “what’s the matter with you” represents a fundamental shift in approach to healthcare. The importance of person-centered approaches and empowerment strategies (see example below) should be recognised and adequately resourced across health and social care in Ireland and should be a key driver of the development of national strategies in this area.

An example of a person-centered approach is the OpenNotes initiative (www.opennotes.org) in the United States of America, the evidence from which suggests that opening up GP visit notes to patients may make care more efficient, improve communication, and may help patients become more actively involved with their health and health care. Over 10 million patients across the USA now have access to their GP visit notes through this programme.

The committee should promote the principles of self management of patients in addition to the care they receive from direct services, towards achieving improvements in health, activity levels, quality of life and mood that is cost effective, sustainable, and applicable to patients across the hospital and community settings (see example below). Investment in clinically effective, chronic disease self-management interventions needs to be prioritised.²

An example of a cross-setting self-management programme is the Better Health, Better Living programme in Beaumont Hospital, Dublin. This six-week programme is based on the model developed by Stanford University, California. To date over 100 patients have been through the programme, learning valuable skills and techniques to assist them in becoming better self-managers of their illness.

2. Integrated care based on sharing of patient and health data

The reorganisation of care delivery in Ireland requires the adoption of patient-centric integrated care³. By putting patients’ care pathways at the centre of the system reform, integrated care systems can deliver improved and tailored health outcomes while creating efficiencies in settings where they are delivered.

Improved electronic information sharing between health and social care providers and their ‘third sector’ partners⁴ is paramount to ensure that the patient receives the right level of care based on a centralised health record. Therefore investment is needed to drive the paradigm shift, moving from a transactional (e.g. eReferral) approach to healthcare to a secure document / record-based system (e.g. Electronic Health Record) built on the foundation of a fully implemented unique patient identifier. Interoperability of existing and

² HIQA Health technology assessment of chronic disease self-management support interventions:

<https://www.hiqa.ie/publications/health-technology-assessment-chronic-disease-self-management-support-interventions>

³ “The organization and management of health services so that people get the care they need, when they need it, in ways that are user friendly, achieve the desired results and provide value for money” (World Health Organization)

⁴ non-governmental and non-profit-making organizations or associations, including charities, voluntary and community groups, cooperatives, etc.

future systems will be paramount as well as citizens and professionals having appropriate access (based on patient consent) to the record no matter where they are in the health and social care system.

Ireland also needs networked patient registries in place to offer value-based healthcare and to improve significantly the ability to share anonymized patient data both within Ireland and across borders. The capability of monitoring the “right patient, right treatment, right time” can be achieved through setting up a centre of excellence that would support the development of networks of high quality, standards-based, disease-specific registries⁵.

3. Rare Diseases and Chronic Diseases

A fundamental aspect of the development and implementation of person-centered, coordinated care in Ireland is that by focusing on those in society who are most vulnerable (e.g. older and younger populations), we will get it right for the rest of the population. This especially applies to those with rare or chronic diseases, who are particularly disadvantaged by the lack of certain services (e.g. clinical genetics and timely access to diagnostics) and treatments in Ireland. IPPOSI recommends that the requirements and needs of rare disease patients⁶ be specifically highlighted as part of the long-term, ten year strategy. IPPOSI also recommends that the strategy focus on solutions for chronic diseases as due to an aging population, chronic diseases account for over 70% of disease burden worldwide⁷.

4. Primacy of Clinical Research

Clinical research needs to be at the core of the Irish health services, embedded within every team and every department, with clinicians supported through adequate research training and incentivised to undertake that work. In addition, clinical trials need to be established as a routine aspect of healthcare in Ireland. Trials allow access to innovative therapies but also the rigour involved in running a trial raises the quality of care across the board. IPPOSI members believe that through enhanced, ring-fenced funding, the positive health and related economic impacts of clinical trials (as were recently published by Cancer Trials Ireland⁸) will be replicated in other clinical areas.

This committee should move to boost clinical research in Ireland through:

- investing in protected time for clinicians who wish to be involved
- a guaranteed career structure for research nurses, data managers & others contributing to healthcare research, integrated within Irish health services
- investment in research networks and associated infrastructures to allow access to trials for patients near to where they live.
- the appointment of a research tsar by the HSE, with a ring-fenced budget, and a clear vision and strategy, would be an important first step in demonstrating cross-

⁵ <http://www.ipposi.ie/images/Towards%20a%20National%20Strategy%20for%20Patients%20Registries%20Report.pdf>

⁶ <http://www.health.gov.ie/blog/publications/national-rare-disease-plan-for-ireland-2014-2018>

⁷ http://health.gov.ie/wp-content/uploads/2014/03/tackling_chronic_disease.pdf

⁸ <http://www.cancertrials.ie/images/uploads/2016%2005%2018%20DKM%20Economic%20Impact%20of%20Cancer%20Research%20Final%20Report.pdf>

party commitment to best practice in clinical treatment, to best innovation in science, and to best outcomes for patients.^{9,10}

5. Access to Health Innovation

The availability of new health innovations (such as new medicines, technologies, devices, processes) is a vital component of a good health service. In recent years challenges have emerged in access to new and often expensive treatments. IPPOSI members believe it is unacceptable for Irish patients to be denied access to health innovations while patients elsewhere in Europe have access.

Transparency and communication are key themes for patients and their organisations within the processes relevant to the approval, assessment and reimbursement of health innovations. The decision-making process to reimburse therefore needs clarity on who the decision maker is and what the criteria for that decision includes. In order to increase transparency and trust in the process, the decision needs to be independent of politics and should directly involve the perspectives of patient representatives.

IPPOSI also recommends that more consideration be made of innovative Early Access Programmes for new medicines and technologies so that Irish patients can be among the first in Europe to have access to new innovations. Early Access Programmes exist in Ireland¹¹ and within other European countries¹² and these should be learned from. This will ensure that once given the green light by the European Medicines Agency, patients can benefit without delay.

6. National framework for scaling up of healthcare innovations

Members of IPPOSI believe that innovation is alive and well in the Irish health system, albeit in a fragmented manner - many innovations are only operational in limited deployments with isolated pilots unable to access the necessary scale-up supports and incentives to make a real difference. Indeed, many updates to the provision of healthcare services often have their origin in patient communities, academia and industry. The success, or failure of these ground-breaking innovations can be determined by the capacity and willingness of the health system to adopt it at a particular time.

A proposed solution is a national framework where public, private and patient thinking on solutions for sustainable healthcare can be harnessed¹³. The Irish Health Innovation Hub¹⁴ is the beginning of this process. However, a longer-term approach is required to include a mechanism by which innovative ideas can be recognized, quickly adopted, scaled up and implemented as well as a formal system to monitor and evaluate innovative ideas.

⁹ http://www.ipposi.ie/images/CRI_Report_May_13th_2008_low_res_1.pdf

¹⁰ <http://www.mrcg.ie/go/news/news/launch-of-the-mrcg-manifesto-for-medical-research>

¹¹ <http://health.gov.ie/wp-content/uploads/2015/07/Final-Public-Health-Plan-for-the-Pharmaceutical-Treatment-of-Hep-C-Final-Copy-Circulated-July-2015.pdf>

¹² http://www.abpi.org.uk/our-work/library/industry/Documents/early_access_to_medicines_scheme.pdf

¹³ http://www.eu-ems.com/summary.asp?event_id=254&page_id=2247

¹⁴ <http://hih.ie/about-hihi>

7. Investment in primary care and front-line staff

IPPOSI encourages the development of a national infrastructure of primary care teams to relieve pressure on acute hospitals. Increasing primary care expenditure will be required to include the appointment of more GPs, practice nurses and public health nursing, alongside allied healthcare professionals, more management of chronic disease in the community, including more care at home.

In addition, to combat the urgent issue of professional burnout across primary, secondary and tertiary systems, the welfare of front-line workers should be paramount. Commitment to work culture improvements (e.g. initiatives such as ‘hellomynameis’) can contribute to a more positive healthcare environment where patient experience is improved and front-line staff feel better appreciated and valued.

Funding Model

The determination of the funding model for a universal, single-tier health service should be guided by the definition and goals of universality. Indeed IPPOSI members question whether the definition of ‘universality’ will extend to both public and private healthcare provision? Patients access services through different schemes and routes so we question how the committee plan to approach the existing public vs private service divide?

IPPOSI believes there is a need to support the integration and interconnection between the health and social care systems. The lack of designated funding for social care forces many families to place a loved one in residential care prematurely, when home help, day-care or respite could have kept them at home. Consequently, vital social care services are increasingly available only to those with the highest needs and lowest incomes, rather than as a universal service supporting the whole population. If increased resources are to be made available, a strategic approach based on increased support for community care should avoid the current ‘see saw effect’ between the primary, secondary and tertiary care settings.

In addition, funding models that are outcomes-based (i.e. activity-based) will only be implementable based on data that is integrated. This can then be used to drive performance-related data collection which will lead the paradigm shift from a service-centered system to a more person-centered one.

The choice of funding model should also be guided by independent evidence developed by organisations such as the Economic and Social Research institute (ESRI). The ultimate decision should be made based upon three criteria¹⁵:

1. Technical merit and likely performance;
2. Feasibility for implementation in relation to the changes required; and
3. The likelihood of support from key stakeholders

¹⁵ Thomas S & Darker C. (2013) What is the right model of universal health insurance for Ireland?. In: Tom O'Connor (eds). *Integrated Care for Ireland in an International context: Challenges for Policy, Institutions & Specific Service User Needs*. 19 Rutland Street, Cork, Ireland: Oak Tree Press.

A 'Benefits statement' could also be provided in order to clarify the patient-level and system-level benefits that will arise from Universal Health Care in terms of access, cost, quality and other metric improvements.

IPPOSI Recommendations

We propose eight solutions which could be affected through the committee's approach to developing a ten-year plan for the Irish health and social care system. These would help to create a system which treats everyone equally, taking account of specific needs, integrates care and is underpinned by a universal, publicly-funded system.

1. Place person-centered, coordinated care very firmly at the heart of future strategies and engagement
2. Move from the current transactional-based approach to healthcare, to an outcomes-based funding model, defined in partnership with patients, to promote sustainability and increase access.
3. IPPOSI encourages a firm commitment to improving the lives of people with rare diseases or chronic diseases.
4. The significant contribution of research and innovation to provide healthcare solutions needs greater recognition and support.
5. The necessity of making anonymised patient data available for care improvement and research purposes is paramount.
6. Increase support for the development of a national infrastructure of primary care teams
7. Directly support the welfare of front-line staff to empower and enable them to shape the future transformation of the system.
8. Increase the capacity and willingness of the health system to adopt and scale-up clinically-effective health innovations.