Mapping and analysing priorities, common themes and gaps in research on good models of care provision in Europe

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TO-REACH - Transfer of Organisational innovations for Resilient, Effective, equitable, Accessible, sustainable and Comprehensive Health Services and System

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1.0   TO-REACH

TO-REACH is a coordination and support action funded through Horizon 2020 Societal Challenge 1. Its goal is to prepare a joint European research programme aimed at producing research evidence supporting health care services and systems to become more resilient, effective, equitable, accessible, sustainable and comprehensive (in Europe, and abroad).

TO-REACH will pursue three main objectives:

-        to produce a Strategic Research Agenda which will identify common priority areas across Europe for a future joint research programme on health services and systems;

-        to broaden the coalition of committed Member States and funding bodies;

-        to develop a structured system of information exchange between public health research funders and other relevant bodies

In order to reach these objectives a framework composed of six work packages has been mapped out. As part of work package 2 national partners of TO-REACH including HRB were tasked with identifying current and upcoming priorities in the organisation of care of policy makers, funders and other stakeholders and to synthesise this with relevant information from roadmaps and strategy documents.

The HRB choose to carry out a survey of key health stakeholders within Ireland to identify the key research priorities and challenges in health systems research within Ireland and Europe and what is needed to resolve these. The data collected through the survey was then mapped to relevant national documentation and the findings described below.

2.0   Survey Description

The HRB conducted a national consultation via an online survey, using Survey Monkey. An invitation-to-participate list was compiled of 673 contacts. The list included HRB public reviewers, HRB grant holders (within the past eight years) and recommended contacts by the Department of Health (DOH). Previous public submission reviews to the Committee on the Future of Healthcare were used to gather further contacts. A breakdown of the contacts provided by the Department of Health can be seen in Table 1 below. In accordance with the To-Reach guidelines the public sector includes: research funders, government departments, health service providers, insurers and public funders of health services and regulatory and supervisory agencies. Those classified as private sector include: research funders, insurers, private health service providers and industry.

Table 1:

Sector	Number
Public	148
Private	4
NGO	12
Academia	22

An email invitation (Appendix 1) was sent on Thursday 19th April to all 673 contacts. Approximately 60 of these did not reach the intended recipient as the email address was no longer valid, the intended recipient was no longer in post or the intended recipient was on leave. The Communications department in HRB also placed the survey on the HRB website as a news story. This meant that any individual who had signed up to receive notifications from the news section of the website would be informed of the survey. Approximately 200 people received notification of the health services and systems research survey via the HRB website.

The survey consisted of 9-11 questions: five to seven demographic (depending on previous answers) and four qualitative questions. A brief narrative introduced each qualitative question. A copy of the survey can be found in Appendix 2. The survey attracted 428 respondents and a total of 203 completed responses (47% completion rate). The survey remained open for 2 weeks from the date of going live.

2.1   Sláintecare report

In May 2017 the Oireachtas Committee on the Future of Healthcare in Ireland published the Sláintecare Report[1] which sets out a strategic plan to transform the Irish health over the next 10 years**. .** The report mostly focuses on: Population Health Profile; Entitlements and Access; Integrated Care; Funding; Implementation. The Committee concluded that the Irish healthcare system ''must be re-orientated to ensure equitable access to a universal single tier system, and that the vast majority of care takes place in the primary and social care settings''[2]. A key recommendation of the report is that every Irish resident will receive healthcare regardless of ability to pay and ensuring the social determinants of health are not overlooked. The Sláintecare Implementation Strategy (SIP)[3] was published in August 2018 and builds on the reforms suggested in the original Sláintecare report. An Advisory Council and a Sláintecare Office within the DOH were set up around the same time. The approach focuses on the vision of Sláintecare and is underpinned by eight principles: engagement, patient is paramount, timely access, care provided free at point of delivery, prevention and public

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[1] https://assets.gov.ie/165/270718095030-1134389-Slaintecare-Report-May-2017.pdf
[2] Committee on the Future of Healthcare. 2017. *Sláintecare.* p12.
[3] https://health.gov.ie/wp-content/uploads/2018/08/Sl%C3%A1intecare-Implementation-Strategy-FINAL.pdf

health, workforce, public money spent only in the public interest and accountability. The above principles guide the framework for development of the Implementation Strategy.

2.2   Irish Population Health Profile

- Ireland has a total population of 4.7 million people[4].
- Life expectancy is 83.5 years for women and 79.3 years for men. This is comparable to the rest of Europe.
- The Irish population is growing (8% growth rate in previous decade) and getting older. It is estimated that 23% of the population will be aged over 60 by 2026. Between 2016 to 2031, those aged 65 and over will increase by 59% and those aged 85 and over will increase by 97%[5]. The older age cohorts remain the highest users of most health and social care services.
- Life expectancy and general health in Ireland is lower for people with a low income[2].
- There is a significant difference in the general health of people aged 50 or over living alone and those living in a family household. 39.5% of people aged 50 or over living in family households classified as having very good health in comparison to 27.2% of the same cohort who live alone[3].
- 53% of the Irish population are overweight or obese[6].
- 28% of the population aged 15 years or over are limited in everyday activities, due to health issues[4].

2.3   Description of Participants

The survey generated 203 complete responses. 178 respondents completed the survey from a personal perspective and 20 on behalf on their organisation, four respondents stated other and one provide no answer. Of the 20 responses completed on behalf of an organisation, 11 were from the public sector, five in academia and four NGOs. Private stakeholders were missing from the responses, although notably, some private health stakeholders were included in the original contact list. The stakeholder groups are as follows:

- Public sector: Health Service Executive (four submissions from unknown departments), HSE Integrated Care Programme for Prevention and Management of Chronic Disease, HSE Integrated Care Programme for Older People, Dublin Dental University Hospital, UCC National Cancer Registry, National Dementia Office, Mental Health Commission and the Health Products Regulatory Authority
- Academia: The Royal College of Surgeons in Ireland (Office of Research and Innovation and one unknown department) and University College Cork (Department of Clinical Therapies and two unknown departments)
- NGO: Irish Hospice Foundation, Care Alliance Ireland, Irish Pharmacy Union and Inclusion Ireland

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[4] Central Statistics Office. *Census 2016.*
[5] Central Statistics Office. *Population and Labour Force Projections for the period 2017-2051*
[6] Central Statistics Office. 2015. *Irish Health Survey*

The HRB received wide support for this research, evident from the large number of responses we received. Throughout the survey, it was noted that this scale and depth of research is a welcome inclusion into health services and systems research within Ireland. Our respondents acknowledged the importance and the need of this type of research and many expressed further interest in assisting with this study.

2.4   Methodology

Thematic analysis was used to analyse the 203 complete survey responses. Thematic analysis is a method for 'identifying, analysing, and reporting patterns (themes) within data'.[7] More specifically, inductive thematic analysis was chosen as it is the process of 'coding the data *without* [emphasis in original] trying to fit it into a pre-existing coding frame, or the researcher's analytic preconceptions'.[8] As the information was gathered using a survey, only a semantic approach was used when identifying themes.

After becoming familiarised with the data, initial codes were generated from the data. All completed responses were given full attention and any common occurrences were extracted. The codes were then assessed and grouped together into themes. The research group then reviewed the themes. This process involved some individual themes coming together and also one theme separating into two themes. This allowed the analysis to be more structured and the content of themes more clear.

The To-Reach reporting guidelines suggested the top 10 domestic priorities to be included in the report, as well as the top 10 European priorities. Nine domestic priorities are reported and seven European priorities. To report on ten priorities for each section would have involved researcher bias as there were only nine and seven dominant themes in the domestic and European priorities.

Please note in analysis, responses submitted on behalf of an organisation were weighted more heavily in comparison to those submitted from a personal perspective. An attempt was made to include all responses from each organisation in the report, even if other organisations did not share that opinion. Not all ideas and opinions were included from those who completed the survey from a personal perspective. Many respondents included their name when completing the survey from a personal perspective. A list was compiled of these individuals comprising of 162 names. Two separate reviews of the names were conducted, highlighting 14 individuals. The responses of the 14 individuals were further analysed. These individuals are known to work with, or within, major health organisations or health academia within Ireland.

3.0   Priorities for Health System Research

3.1   Domestic Research Priorities

The question on the top 5 priorities for health services and systems research was the only compulsory question within the survey and, as such, was the most commonly answered. Many of the

[7] Braun, V. and Clarke, V. 2006. 'Using thematic analysis in psychology' *Qualitative Research in Psychology,* 3(2) pp: 77-101
[8] Ibid, pp 12

responses did not recognise all aspects of the question. The top five priorities for health services and systems research within Ireland was well addressed, however very few respondents explained or acknowledged what challenges in the health system the priority, or priorities, addressed. This impacted on the analysis and a higher focus was on the responses that fully engaged with this question. Some responses also seemed to focus on issues around service provision rather than identifying the research questions that might arise out of these.

3.1.1   Ageing Population

At a population level, Ireland has seen improvements in health status and other health outcomes. Life expectancy has increased more rapidly than in many other EU countries and the number of people aged 65 and over is set to double from 12.4% to 24.9% by 2050[9]. With an ageing population comes a different demand from the health system and a need to establish supports that will (hopefully) keep the burden on Ireland's health system manageable. It was suggested that research is conducted into identifying dependency models that support *''a long term approach to service planning for older people and changing needs over time''* as well as education models for professionals, undergraduates and postgraduates. The Sláintecare report[10] addressed the need for a ''new model of coordinated health and social care'' to accommodate the growing ageing population, to include chronic and disabling conditions, and to respond to ''individual wishes and circumstances… and be organisationally efficient and cost-effective.''

The research area of an ageing population involves many subsections. However after first analysis, the rapid growth of Ireland's ageing population and how to accommodate this is the number one ranked research priority. Research into living situations is a notable aspect. This includes the availability, location and affordability of nursing homes, but more preferably how to adapt the individual's current home to be more age friendly. How to increase the support elderly receive in their own communities, to increase their quality of life and how to hinder/ avoid loneliness and isolation are included in this. The lack of integrated pathways for elderly *''living with multiple health problems and polypharmacy challenges in diverse settings''* was also highlighted as a research priority for Ireland, calling for the need for evidence based end to end pathways. A recent study by TILDA found that 72% of community dwelling older people do not have access to public health nursing[11].

The number of individuals identifying as a family carer has increased significantly in Ireland[2]. Alongside accommodating for an ageing population, Ireland needs to take into consideration the health of all individuals identifying as a family carer, for a range of health related issues. The specific health difficulties – mental, emotional and/or physical - that family carers face is becoming more prevalent. Our respondents saw Ireland's ageing population and the changing demand on the health system as a major research priority; however it was not frequently mentioned throughout Sláintecare in comparison to other topics.

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[9] Amárach Research, Lyons. R., Sirr, L. and Innovation Delivery. 2016. *Housing for Older People- Thinking Ahead.* Ireland Smart Ageing Exchange and the Housing Agency

[10] Committee on the Future of Healthcare. 2017. *Sláintecare Report.* p71

[11] Roe, L., O'Halloran, A., Normand, C. and Murphy, C. 2016. *The Impact of frailty on public health nurse service utilisation.* TILDA.

Ireland needs to address alternatives to residential care. Community care is not a statutory entitlement. Specifically, survey respondents saw the need to research since it would *"cost the state less to provide more care in the community and prevent or delay long-term care".* Existing care packages are expensive to both the state and families and so it would be of benefit to all to find suitable, more cost-effective models. It is important to ensure the autonomy of the individual and their quality of life is paramount in any potential change.[12] Alternatives to residential care are also an important concern for people with disabilities and those suffering with mental health issues and are not specific to an ageing population.

3.1.2 Waiting times

As noted earlier, not all respondents provided sufficiently in-depth answers. This heavily applies to the discussion of waiting times in responses. However, it was evident that the length of waiting times within the Irish health system is of major concern to the Irish stakeholders. It is therefore the second research priority. The Euro Health Consumer Index 2017 places Ireland 24th out of 35 countries in relation to healthcare waiting times. In 2015 10% of outpatients had to wait over a year to get access to services.[13] Sláintecare noted the long waiting lists as one of the "scourges of the current Irish healthcare system".[14] Respondents noted that the lengthy waiting times in Irish health services are also related to numerous other issues within the system such as bed capacity, staff numbers, changing demographics and the general health system structure. Research into reducing waiting times would likely include investigation into these areas, amongst others.

Addressing waiting times, in particular for hospital procedures, was a main priority in the 2016 Programme for Partnership Government, however there has been little impact. The Sláintecare report noted that widening the health workforce would not be sufficient in ensuring waiting times are reduced[5]. It also acknowledged the need to establish maximum waiting time guarantees and to "make people accountable for these guarantees" and highlighted the success of other European countries that enforce guarantee waiting times, including England (hospital penalisation) and the Netherlands (other care options).[15] Sláintecare suggested a wait time of less than "12 weeks for an inpatient procedure, 10 weeks for an outpatient appointment and 10 days for a diagnostic test" and that waiting lists are published by facility and speciality[6]. The issue of capacity and waiting lists can be solved by addressing the "re-orientation of our system towards primary and social care" and the disentanglement of public and private healthcare.[16] The Health Service Capacity Review 2018 will help guide this change. SIP outlines multiple Waiting List Action Plans to be completed by 2019 and the development of hospital services within a national clinical strategy, amongst other approaches, all aiming to decrease waiting times.

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[12] OECD. 2018. *Improving the Lives of People with Dementia.*
[13] European Commission. 2017. *State of Health in the EU: Ireland – country health profile 2017.*
[14] Committee on the Future of Healthcare. 2017. *Sláintecare Report.* p81.
[15] Ibid, p 82.
[16] Ibid, p 51.

3.1.3   Primary care and universal access

Ireland has very little universal entitlements to healthcare and eligibility only for some services. Healthcare in Ireland is extremely hospital centric and people are often cared for within a hospital rather than a community setting. The current set-up of integrated private and public healthcare contributes to the above challenge of very long waiting times. Those with private medical insurance (over 40% of the population[13]) can receive healthcare within a public hospital and are often seen before those without private health insurance. Medical cards and GP visit cards, both means tested are available via public healthcare. A Medical Card ensures the holder does not have to pay to see a GP, or for prescribed medicines, although prescription charges may apply. They receive free public in-patient and out-patient services, dental checks and ear and eye tests. In 2016 36% of the population had a Medical Card.[17] Nearly 10% had a GP Visit Card which provides free GP visits for card holders.[13] Those of the population aged over 70 years old and under 6 years old automatically qualify for a GP Visit Card.

A redesign of primary care and what it involves is necessary to move towards needs-based access. Primary care, according to the Department of Health, is where ''the vast majority of healthcare needs can be addressed at the most appropriate level of complexity and most cost-effectively''.[18] Survey respondents call for access to GP services to be made more affordable and accessible. Most recent data shows that Ireland has 2.9 Doctors per 1000 of the population; this is lower than the OECD average of 3.4.[19] Ireland is set to lose over 660 GPs due to retirement within the next five years.[20] The number of applicants for GP posts is in decline. This is a major concern, especially in rural areas were GP posts will often receive no applicants.[15]

The Sláintecare report noted GP services as ''critical to providing high quality integrated care''[21]. The range of services they offer needs to be addressed as well as how best to improve on the services received, and those services available, within primary care. Respondents noted that GPs should have easier access to diagnostic tools which would take pressure off from accident and emergency departments in hospitals, as currently many people end up in an Emergency Department for a diagnostic test. Appropriate standardised care pathways should be acknowledged.

The over reliance on hospital based acute health care, and the lack of community-based and social care infra-structure lead to ''*fragmentation, duplication and silo-ing of services and research*'' which makes healthcare accessibility difficult, notably for those without private health insurance. The development of primary care is crucial. Patients should be seen locally (or within their home if necessary). Better management of primary care would assist in reducing the numbers admitted to Emergency Departments, for example, the removal of fracture clinics and minor injuries to primary care facilities. Specifically, the development of primary care centres to relieve pressure and allow people to be assessed locally, then directed to a focused service if necessary. The DoH's Statement of Strategy stated that ''funding commitment for 80 additional primary care centres'' had been secured[22]. 2018 saw the opening of 12 new primary care centres and seven more planned within the

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[17] www.health.gov.ie/wp-content/uploads/2018/01/Key-Trends.pdf

[18] Department of Health. 2016. *Statement of Strategy 2016-2019.*p 13.

[19] OECD. 2017. *Health at a Glance 2017: OECD Indicators.* OECD Publishing, Paris.

[20] Irish Medical Organisation. 2017. *Annual Report.*

[21] Committee on the Future of Healthcare. 2017. *Sláintecare Report.* p 63.

[22] Department of Health. 2016. *Statement of Strategy 2016-201,* p24.

year. The total number of primary care centres in operation is 120[23]. Sláintecare recommend implementing diagnostic centres within these centres.

The Sláintecare report advised that ''the best health outcomes and value for money can be achieved by re-orientating the model of care towards primary and community care''[24]. This would include research into what might be covered under universal healthcare and possible execution strategies. Sláintecare noted that universal healthcare would need to include ''timely access to all health and social care according to medical need; care provided free at point of delivery based entirely on clinical need; patients accessing care at most appropriate, cost effective service level with a strong emphasis on prevention and public health''[25]. It was suggested within the Sláintecare report that over €770 million be invested in universal GP care, universal primary care and universal palliative care over the first 5 years of the healthcare plan to address this. The SIP discusses the expansion of general practice and community nursing and the development of community-based services in cohesion with population needs.

3.1.4   eHealth

The eHealth Strategy for Ireland ''identifies a set of objectives to be achieved and proposes a roadmap for their implementation within an outcomes-based delivery model''.[26] The radical changing of Ireland's healthcare demands means that the future healthcare system will also need to be radically different to respond to demand. The development of eHealth within the Irish healthcare system was a common research priority and the Sláintecare report noted eHealth as ''the critical enabler to implement the change required to deliver an integrated, universal, high quality health system''.[27] There is a desire for Ireland to move away from paper records and move to a centralised interactive system that would be accessible (as required) by frontline health workers such as GPs, consultants, pharmacists and social workers. This may help make the system more efficient and hence reduce costs. eHealth records would provide a ''*complete picture of overall health and medication''* of the individual which may help individuals receive quicker and more applicable treatment and provide better continuity of care. It would also ensure patient centred delivery and a likely increase in patient safety.

Mr Tony O'Brien, then HSE Director General, stated to the Committee on the Future of Healthcare that individual health identifiers will be put into use in 2018. However this has not yet happened universally. Electronic Health Records are currently being piloted in the Cork and Kerry regions in the public maternity service. Also of note are the three Lighthouse Projects aiming to understand the benefits of implementing electronic health records within the Irish healthcare system. The projects are in the areas of Bipolar Disorder, Haemophilia, and Epilepsy. Each project has specific deliverables and is in collaboration with a number of different organisations. These include the development of patient portals to enable, and improve, self-management.

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[23] Government of Ireland. 2018. *Sláintecare Implementation Strategy*.
[24] Committee on the Future of Healthcare. 2017. *Sláintecare Report* , p77.
[25] Ibid, p38.
[26] HSE and Department of Health.2013. *eHealth Strategy for Ireland, p4.*
[27] Committee on the Future of Healthcare. 2017. *Sláintecare Report,* p103.

Access to individual electronic health data could ensure a smoother movement for patients between ''*primary care, secondary care and public and tax-subsidised private*'' care and better integration which could lead to prevention of ''*duplicate test ordering, delays on results and hospital discharge*''. IHI would also enable a new and advanced research agenda to inform improved economic forecasting and service planning, as well as health decisions to be evidence based. Currently, the data being collected ''*does not serve the needs of the population groups*'' as there is no sufficient evidence to ''*inform estimates and business case programmes*''. Proper ''*prevalence, incidence and multimorbidity data*'' and population based data is of importance going forward to assist in economic forecasting and developing new service needs, for example ''*chronic disease management and self-management of chronic disease care*''. A national ICT system that enables researchers access to routine health data, including common coding and measurement practices for comparability would be of benefit to Irelands health system.

Sláintecare acknowledged the importance and need for an electronic health record in Ireland and emphasised the support and funding required for this to be implemented throughout the country as well as its central contribution to the ''successful delivery of integrated care''.[28] SIP reiterates the importance for eHealth, sets out processes to implement electronic health record system, develop IT infrastructure and related information and research.[29]

3.1.5   Health promotion

There was a strong desire from the respondents for Ireland to change from a ''*treating*'' culture and move to a ''*preventative*'' healthcare culture. One respondent commented that ''*our current system is based on throwing life buoys in when people are drowning*''. This shift would start with education to the whole population on various topics, notably healthy eating and physical activity. Obesity is growing in Ireland with 61% of all adults and 25% of three year olds overweight or obese. Healthy Ireland noted the annual estimated cost of obesity is €1.13 billion and presents a ''clinical, social and financial challenge'' with a detrimental legacy[30]. Education is also required on warning signs of major health issues such as addiction, stress, dementia and other mental health conditions. Ireland needs to find out how to eliminate or limit ''*potential long-term effects of lifestyle related conditions*''. If Ireland changes its focus to prevention, our healthcare services may ''*not be under so much pressure*''. Most respondents only referred to education and did not acknowledge the need for behaviour change at an individual level as a result of health promotion. One respondent noted the development of a public awareness campaign with an integrated behaviour change plan. For example use ''*shock tactics, similar to the smoking campaign, to highlight the dangers of a poor lifestyle*'' and develop ''*lifestyle behaviour change programmes to compliment health promotion campaigns*''.

Health promotion research must also include a focus on health inequalities. There are some major issues in this area. For example, poverty is a developing issue in Ireland. A report by the Central Statistics Office showed that one in six people in Ireland are at risk of poverty, the 12th highest in the

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[28] Committee on the Future of Healthcare. 2017. *Sláintecare Report,* p100
[29] Government of Ireland. 2018. *Sláintecare Implementation Strategy*.
[30] Department of Health. 2013. *Healthy Ireland: a Framework for Improved Health and Wellbeing*, p10.

EU[31]. Research into health inequalities includes service delivery design to ensure the needs of vulnerable populations are being met, prioritisation of delivery based on healthcare need, who experiences barriers in *''accessing proactive and responsive care''* and the impact of social issues on people's health. Assessment into the effects of *''health inequalities of all the proposed policy changes''* was also suggested. Fiscal population health measures such as *''tobacco tax, sugar tax and alcohol tax''* may assist to ''narrow the gap in health inequality''.

Healthy Ireland, a ''national framework for action to improve the health and wellbeing of the population of Ireland'' was published in 2013. 'Healthy Ireland in the Health Services'[32] followed as the National Implementation Plan 2015 – 2017, with a number of regional plans being published in 2018. This is accompanied by an annual survey.

3.1.6   Mental health

Mental health is an increasing health, economic and social issue in Ireland and depressive mental illnesses are expected to be the primary source of chronic disease by 2030[33]. The economic cost of mental health in Ireland is €11billion per year[34]. Our respondents noted that research needs to be conducted into establishing a *''standardised integrated care pathway''* for those who suffer from mental health problems including social, psychological, personal and medical. There needs to be consistency in this at national, regional and local level. Respondents acknowledged the current culture of *''failure to provide comprehensive treatment''* and a lack of a multidisciplinary approach to mental health that currently exists within Ireland. Mental health should be included in a reform of primary care. Sláintecare suggests the government providing €5 million over two years to develop psychology services in primary care and over €40 million to establish adult community mental health teams as services are ''overly reliant on medication rather than psychological and counselling services''[35] and are understaffed by approximately 20%[36].

Child and adolescent mental health services are majorly under resourced in Ireland. The mortality rate from suicide aged 15-24 years is the fourth highest in the EU[37]. It is suggested that research is carried out to investigate the *''extent of pressure placed on children and young people via technology''* and the provision of appropriate services to cope with these pressures. It is important that Ireland prioritises mental health *''especially for young people and to be proactive as opposed to being reactive''* on this issue. The Sláintecare report acknowledges the need for this and suggests €45 million to be invested in child and adolescent mental health teams[38] to develop practices.

Respondents suggested making social services are available at weekends. It is also important to invest in education on mental health and the skills required on how to deal with it. Not addressing

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[31] Central Statistics Office. 2016. *Measuring Ireland's Progress.*
[32] https://www.hse.ie/eng/about/who/healthwellbeing/healthy-ireland/healthy-ireland-in-the-health-services-implementation-plan-2015-2017.pdf
[33] Department of Health. 2013. *Healthy Ireland: a framework for improved health and wellbeing.*
[34] Ibid*.*
[35] Committee on the Future of Healthcare. 2017. *Sláintecare.* p6.
[36] HSE. 2017. *Performance Profile: October – December 2017: Quarterly Report.*
[37] Department of Health. 2013. *Healthy Ireland: a framework for improved health and wellbeing.*
[38] Committee on the Future of Healthcare. 2017. *Sláintecare.*

mental health problems can have a negative impact further on in life and lead to unnecessary pressure on the health system, *''early diagnosis… and targeted support are important in preventing escalations''*. The HSE has acknowledged recruitment issues throughout all sections of mental health services. The Child Adolescent Acute Inpatient Units Waiting List Initiative, aims to ensure no one waits over 12 months, continues to operate and the Department of Public Expenditure has approved recruitment of 120 new Assistant Psychology posts within primary care[39]. This is evidence that Ireland is attempting to improve on their mental health services.

3.1.7   Organisational structure

Respondents noted that the general organisational structure of the Irish healthcare system needs to be addressed. This interacts with the lack of affordable and accessible primary care in Ireland, which impacts on waiting lists and other issues noted as research priorities by our respondents. Research needs to be carried out into making the Irish healthcare system more accountable and more transparent. This would include investigation into various models of case management and outcome measures that could be implemented within the Irish healthcare system to provide more accountability within the service. The current format was frequently described as *''too bureaucratic''* throughout the survey. The administration centric environment and heavy management culture *''means funds not being spent on essential front line services''*.

The Irish stakeholders see an organisational restructure as crucial in addressing the current accessibility issues as well as making the health system more cost effective. The development and implementation of quality assurance strategies would address patient safety, and health and safety regulations, as well as including research and evidence to support decision making processes. HIQA state that ''effective leadership, governance and management'' are necessary for the continuous delivery of ''safe, effective person-centred care and support''[40]. Including medical schools and teaching hospitals within health planning was also noted, notably their geographic boundaries. For example, hospitals appear to be distributed so that *''each of the medical schools has their own hospital group. This has led to the situation where Waterford is now effectively run from Cork, and cut off from the relationship it would normally have with Kilkenny and Wexford''*. The upcoming geo-alignment of hospital groups with the Community Healthcare Organisations may change some of the boundaries.

The Sláintecare report stated that the ''current HSE governance structure is not fit for purpose'' and discussed the need for a ''more strategic model of national service level management and coordination''[41] which is also desired by the respondents. A new, independent Board of the HSE was set up, with the Chair appointed in September 2018 and other members in January 2019. The development of a '*national health service centre*' would ensure core functions are carried out at national level, such as strategy and service planning and operations management for example. This should have a positive impact on the creation of an integrated health service and provide a clinical governance approach. Sláintecare noted the need for development of clinical governance

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[39] HSE. 2017. *Performance Profile: October – December 2017: Quarterly Report*
[40] HIQA. 2012. *National Standards for Safe Better Healthcare.* p84
[41] Committee on the Future of Healthcare. 2017. *Sláintecare* p.83.

frameworks within Ireland's healthcare system[42]. The Sláintecare Implementation Strategy have stated to 'Improve governance, performance and accountability across the health service'[43] as their first strategic action. This includes the development of national and regional governance and structures. SIP also acknowledges the importance of continuing to enhance leadership and accountability and building organisational capacity.[40]

3.1.8   Healthcare workforce

Ireland has a high rate of doctor and medical staff emigration which affects the delivery of care. A report by the Royal College of Surgeons in Ireland found that only 41% of medical trainees planned to stay in Ireland[44]. Another research priority is the retention rate of staff. Medical staff in Ireland are often as overworked. More needs to be done to increase job satisfaction and to reduce work related stress in order to decrease the number of individuals leaving Ireland after qualifying. Providing medical staff with more authority and responsibility may also be of use here. The HRB is funding health and care practitioners along their research career path; however the number of awards is limited and the integration of research into clinical roles has been a perennial issue. Research should be carried out on the costs and benefits of *''expanding nurse practitioners/ nurse consultant roles and responsibilities in primary and secondary care''* for example. It must be acknowledged that the SIP addresses the need to develop the roles of nurse practitioners. Another suggestion was to introduce an obligatory period for graduates to *''participate in the system once qualified''*, this would have to be flexible and not prevent the individual *''gaining valuable experience in other geographies''*.

Concerns voiced by our respondents are in aligned with those mentioned in the Sláintecare report. Working conditions must be addressed to entice health service staff back to Ireland and ensure a safe and healthy working environment. Sláintecare highlighted the need to promote best skill-mix and reinforced the need for an ''integrated workforce planning capacity within government''[45]. The ongoing National Integrated Strategic Framework for Health Workforce Planning is a welcome addition and the SIP acknowledges the ongoing assessment of the overall health workforce required to deliver community-based care including addressing existing health professionals' contracts.[46]

Recommendations made in the 2014 Strategic Review of Medical Training and Career Structure have resulted in some positive outcomes for the healthcare workforce, including: career planning information, flexible training schemes and reduced paperwork.

3.1.9   Assessment of practices

Our respondents see health economic assessments of existing practices, including the *''rationalisation of services''* as an important priority in health services and systems research in order

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[42] Ibid.

[43] Government of Ireland. 2018. *Sláintecare Implementation Strategy*. p. 15.

[44] Brugha, R., Cronin, F. and Clarke, N. 2018. *Retaining Our Doctors: Medical Workforce Evidence 2013-2018.* RCSI Health Workforce Research Group.

[45] Committee on the Future of Healthcare. 2017. *Sláintecare*.

[46] Government of Ireland. 2018. *Sláintecare Implementation Strategy.*

to help "balance cost and efficiency". Research should also be conducted into *implementation science*" and evidence based interventions. This would refer to how best to scale successful local initiatives into being successful nationally. Sláintecare supports this priority as it suggests the introduction of an "effective monitoring and evaluation system" in order for new policies and procedures to be based on "the best possible evidence supported by appropriate and accurate information"[47]. A National Framework for the conduct of clinical services is expected in 2019, which will ensure a 'consistent and evidence base[d] approach is taken' when reviewing services[48]. Infrastructure is already in place for the use of Health Technology Assessment (HTA), which is overseen by HIQA (Health Information and Quality Authority). HTA "offers a rational, equitable and objective" process in deciding service provision and prioritisation of resources.

3.2 European Research Priorities

Many of our respondents noted the similarity between the questions asking for domestic research priorities and European research priorities and acknowledged that their previous answer was also applicable to this question. We did not specifically ask our respondents to note which health system challenge their suggested European research priority would help address. It was noted in this section that any health services and systems research organised at European level would need to address "*contextual and implementation issues specific to Ireland*". However, any joined-up-thinking and research at European level would "*ensure quality research could impact on practices, services and systems*". Pan European research may also result in the avoidance of duplication, wider access to qualified personnel and more cost effective methods. Respondents acknowledged that most health services and systems research would be beneficial at European level and research funding, in general should be increased.

3.2.1 Common health trends

Common diseases such as cancer, chronic disease (including management), diabetes, heart and stroke, and mental health (including child and adolescent mental health) and dementia would see value in organising research at a European level. This was due to their common occurrences in other countries as well as in Ireland. By including multiple partners in these areas of research, more funding is likely to be available as well as a wider range of knowledge and skill sets from specialists, which will increase knowledge on the disease as well as medications and cures. These responses did not focus on health systems research, but included areas of clinical and biomedical research. Research into integrated care after a major illness, such as cancer or stroke, would be of benefit. It was also noted that the formation of a rare disease database is more logical on a wider European scale.

As many European countries are now have an ageing population, respondents noted the benefit of sharing research in areas such as models of case management and dependency (specifically for the elderly), optimal medication management and rehabilitation models, for example.

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[47] Committee on the Future of Healthcare. 2017. *Sláintecare*. p140.
[48] Government of Ireland. 2018. *Sláintecare Implementation Strategy.* p.34.

3.2.2 International standards

The development of best practice and benchmarking standards was considered important. European developed national guidelines and audits may assist struggling healthcare systems to improve but it may also mean the transfer of healthcare solutions could be more achievable as there will be similar standards in place. For Irish stakeholders, it is important our healthcare system becomes more efficient as well as providing quality and accountability in healthcare. This can be aided by having guidelines and standards of which to follow.

3.2.3 Healthcare models

As noted previously, basic primary care can be difficult to access in Ireland and a universal healthcare system is desired. Our respondents feel that research into different healthcare models will be of benefit on a European level as, again, there will be a larger financial support and a wide range of knowledge and skill sets that may be utilised. Healthcare models highlighted by the respondents were funding models, care pathways, models addressing health inequalities and medication management. Dependency models ''*that support a long-term approach to service planning... and changing needs over time*'' and rehabilitation ''across a continuum of care'' that can ''*sustain service provision at scalable levels*'' are also of particular importance at European level. It may also be of benefit to address staffing models. This may include dealing with restrictive work practices and reorganising roles and responsibilities of nurse practitioners and nurse consultants, as well as professional education. Research into healthcare models at this level may provide a deeper insight into how and why they are successful within a particular setting. One respondent also noted that the models of care that ''*need to be evaluated to support older people at systematic levels in the face of existing and future demographics remain to be evaluated*''.

3.2.4 eHealth

The development of technology and its use within healthcare was a common theme throughout our entire survey. Our respondents believe eHealth is an important European research investment and one that should be investigated and implemented throughout Europe. A ''*core European eHealth data infrastructure*'' that shared the core needs of European practitioners is important and would create research opportunities to improve services. This could eventually lead to an individual's record being accessible anywhere within Europe, if necessary, and in line with data protection legislation. Some respondents also noted a European wide investment in medicines and diagnostic technology would be of major benefit to all countries involved.

3.2.5 Models of care

Survey respondents saw the potential to improve the ways care is delivered in Ireland by learning from other countries and by sharing examples of good practice and of barriers to implementation. For example, universal access to healthcare is a major topic in Ireland and the shift to community care accompanies this. It would be of benefit to carry out research at a European level into innovative community based primary care and public health initiatives that reduce reliance on hospital based service delivery, and promote integration of current services and systems. Learning

from other countries could potentially assist with Ireland addressing the issue of long waiting times in hospitals and for consultations. Initiatives may include technologies but one respondent noted that this could include ''innovative integrative'' work with local councils and NGOs amongst others. Information on primary care and access to healthcare could be communicated at European level as part of a ''knowledge sharing platform''.

Research on how pharmacy-based services could benefit patients and the healthcare service ''in a more efficient and cost-effective way'' would be important. Pharmacies are the most accessible part of the healthcare system. Research into pharmacy services such as chronic disease management, extended vaccination services, pharmacist-led prescribing, minor ailment scheme, monitored dosage system dispensing for elderly on polypharmacy and health checks could be of use to the Irish healthcare system. It is also important to ensure the citizen is at the centre of any health-related research and to address the ''psychological impact of accessing healthcare that many find challenging to address''.

3.2.6   Data

Population level data, geographical data, and deprivation levels are useful tools to inform population health planning according to our respondents. An integrated system that allows for analysis of data across ''traditional healthcare silos'' would be of benefit at a European level. Comparable national registries for chronic conditions, for example, would be useful in healthcare planning and development. European wide co-ordinated data set has the ability to ''improve human and team performance, optimise individual patient pathways and ensure value for money for health spending''.

3.2.7   Antimicrobial resistance

Ireland has contributed to, and continues to progress research into antimicrobial resistance. For example, Ireland contributes to 'One Health' and the Joint Programming Initiative on Antimicrobial Resistance. 'One Health' is an international approach to the designing and implementation of programmes, policy legislation and research. It includes a wide range of sectors, with a focus on combating antibiotic resistance, the control of zoonoses and food safety. The overall aim is to achieve better public health. Ireland is also among the 26 partners in the 'Joint Programming Initiative on Antimicrobial Resistance'. This includes exploratory research on new antibiotics; stewardship of existing antibiotics; studies and control of the spread of antibiotic resistance between humans, animals and the environment. However, some respondents are either not aware of the large body of work Ireland has contributed to, or believe it is not enough, as it is some respondents' belief that Ireland is doing little to address the ''global threat of antibiotic resistance''. Due to human travel, resistant microorganisms can travel around the world quickly and ''resistant bacteria that emerge in one country can rapidly spread''. It was suggested to have a European wide antibiotic resistance research cohort as the basics of health infection control can be applied to every healthcare setting.

4.0   Transferring Knowledge and Capacity

The HRB survey focused on what the Irish stakeholders believe are the key conditions for the effective and appropriate transfer of healthcare solutions between health systems across different countries. 178 out of the 203 respondents provided an answer to this question. We did not ask respondents for examples of innovations within our country which had been adopted or may be worth adopting for other countries. We also did not ask for innovation examples from other countries that may be in use within Ireland, or that our respondents think should be in use.

4.1   Communication

From the 178 responses, communication was the most frequently noted condition. Communication between all key stakeholders was considered vital. This would include inter-disciplinary communication, and collaboration and within different skill levels, to establish agreed terminology and taxonomies. Transparency on the decision making regarding health services and systems within countries was also suggested. This would help to transfer particular interventions or services in other settings.

Regular communication from the initiation of an individual project was recommended. This would involve countries ''*ironing out problems before they become intractable and share expertise to realise the most appropriate solutions for each country based on a European evidence template''*. A ''dedicated co-ordination group'' was also suggested that would provide ''*a single point of communication for each country''*. The openness of communication will also include language barriers and how to overcome this as well as the understanding of cultural idiosyncrasies. The motivation and willingness to share is undoubtedly important.

4.2   European Research Centre

Alongside this a dedicated European Research Centre was a common suggestion. This would facilitate communication and reliable information transfer and provide a greater scope for access to previously conducted and current studies. The Centre would have to be a ''*neutral information repository''* and would ''*not be linked to any higher education institute or a country dependent organisation''*. The dissemination of data could be focused here as well as the establishment and policing of common coding practices and the possibility to assist with data collection.

Each report of healthcare solutions (or potential healthcare solutions) would need to include a ''*rigorous methodology''* in order to fully understand trial design, the effectiveness of the solution, how best to implement it and the evaluation process for comparison purposes. The context of the health system of where the solution is being implemented should also be communicated as well as high quality evidence about the ''*determinants of effectiveness''* – why this particular solution works.

Having a European Research Centre would assist in the ''*application of common standards''*, that ''*documentation and procedures are standardised''* and ensure a ''*transparent process evaluation''* and the reporting of high quality evidence. Common coding approaches within research may also need to be acknowledged. Our respondents noted that awareness of particular aspects of conditions may be required in the transfer country for healthcare solutions to be effectively transferred.

4.3   Technology

In order to facilitate effective and appropriate transfer of healthcare solutions, Irish stakeholders noted the use of technology as a key condition. However, this suggestion was not described in much detail. An integrated technology system was recommended that would include *"inter-operable healthcare records"* as well as electronic prescribing. It was noted that this would require policing, regular updates and strong data protection. With a common technology platform, anonymised and protected patient and/or healthcare system data may become more accessible for research. Developing an "open source attitude to knowledge" was suggested. 'Open source' ethos includes "transparency, peer production and collaboration". It is currently used in biological and biomedical research. The importance of data protection and General Data Protection Regulation was noted. A database of rare diseases at European level was considered important although it was not specified what useful information this database might include.

5.0   Barriers and facilitators to Health Systems Research Funding and Organisation

For this section in the survey, the HRB survey focused on what needs to happen to support the implementation of health systems research. Specifically, we asked our respondents to make suggestions as to what could be done to enable the growth and improved relevance and reach of health services and systems research within Ireland. This was the question in the survey with the least responses; 175 responses (86%) out of 203 completed surveys. The majority of answers related to the lack of communication between (and within) the Health Service Executive and the Department of Health as well as the lack of communication with the public regarding health research and health advancements. This leads into how the health system is reported in Ireland and the effect this has on the public support.

5.1   Communication

Communication between and within stakeholders related to Irelands health system is weak and hinders the progress and implementation of effective research. Collaboration between policy makers, healthcare leads and researchers should become more widespread. This is to ensure that there is awareness as to what is being done in elsewhere, to "avoid duplication" and to "*ensure comprehensive solutions are implemented*". Healthcare delivery in Ireland, as well as research, is often completed in isolation. A number of HRB funding schemes are designed to further those collaborations. The Sláintecare Implementation Strategy discusses the need and steps to develop engagement with, and between, various stakeholders. The health system needs to work to "*overcome specialisation silos*".

Better communication channels need to be introduced between the health service and patients, with the increase of patient and practitioner surveys such as the National Patient Experience Survey. It asks people to discuss their recent hospital experience with the aim of finding what works well, what does not, and to help prioritise areas for improvement.

Our respondents believe that the achievements arising from research could be shared more widely and the information made more accessible. One respondent noted the HRB Open Journal (an open online publishing platform) as a *''welcome development''* in this direction. However respondents also noted that research needs to be made more public and more accessible to the Irish population. There is a strong sense that most people living in Ireland are unaware and have *''little appreciation of the research being done, its scale, impact and outcomes''*. Promotion of accessible fora to share this information, at all stages of the research process, may be helpful.

5.2   Media

The media coverage of healthcare in Ireland is mostly negative and the *''successes have limited publicity''*. Our respondents believe that a change in the communication agenda and *''better communication of the significant advancements''* made within the health system is needed. This will inform the Irish population that investment is being made into improving their healthcare, the health system and hopefully *''foster confidence in and acceptance of the services on offer''*. Respondents noted that the constant negative reporting may be a factor contributing to *''poor investment into research by the private sector''*.

5.3   Funding

More investment and research support was suggested to increase and assist the quality of health systems research within Ireland. This may include more grants available to a wider range of applicants at various stages of their career, as well as a wider range of topics. One suggestion was to use policy to help fund specific research areas, for example, use money gained from introducing a sugar tax to increase awareness of and research into obesity. Continuing to build capacity around Public and Patient Involvement approaches to interventions and research was important to our respondents as this will help maximise *''the connections between research, policy and practice in the health* sector.''

5.4   Research agenda

The research agenda needs to be focused on the priorities of the health service. There needs to be a *''dynamic cycle''* between the research community and the health service so that research priorities are *''relevant''* and *''timely''*. This would allow for *''true population health planning''* as long as there is state and private providers collaborating and input from the general population. It is important that a wide range of sectors and voices are included in research. Ireland is a small country with a *''limited pool of experts and the views of a small few can sometimes over-influence policy and research''*. More integration with *''public facing organisations''* and the involvement of *''people and their carers''* in research and service development, including a professional career structure, is called for.

Appendix 1: Invitation to Participate

Dear

You are invited to participate in a survey identifying current and upcoming health services and systems research priorities within Ireland and the EU. The survey is run by the Health Research Board and will feed into a bigger European project. We wish to hear from a wide range of voices including public and private service providers, patients, carers, academics and industry professionals – this includes you.

Ireland's health system is facing challenges arising from rapid demographic, environmental and technological change. We need to strengthen and transform our health system, and we need evidence to guide the best ways of doing this. Health services and systems research investigates how social factors, financing systems, organisational structures and processes, health technologies, and personal behaviours affect access to health care, the quality and cost of healthcare and ultimately health and well-being. It improves the efficiency and effectiveness of health professionals and the health care system through supporting the development, transfer and uptake of solutions. Health services and systems research underpin changes to practice and policy with the aim of an equitable and effective health system.

This survey is part of the To-Reach project, a project funded by the Horizon 2020 programme of the European Union. Horizon 2020 is the main EU funding programme for research and development. The goal of To-Reach is to prepare a joint European research programme which will support health care services systems to become more resilient, effective, equitable, accessible, sustainable and comprehensive. As different health systems face many common challenges, there is an opportunity to share knowledge, expertise and resources in order to enable a larger societal impact.

The HRB over a number of years has purposefully invested in health services and systems research – in people, projects and networks. The learnings from this survey will help the HRB to develop and plan for future strategies in this space.

In May 2017 the Oireachtas Committee on the Future of Healthcare in Ireland published the Sláintecare report which outlines a significant programme of health reform over the next 10 years. The Sláintecare report, along with other relevant documents, will help to guide the Irish response to To-Reach.

We would like to draw on your expertise to ensure that different perspectives are taken into account in the research agenda. We look forward to hearing from you. Thank you for your contribution and please feel free to share.

The survey should take less than 15 minutes to complete, depending on the length of your answers, and will close on Friday 4th May at 5pm.

If you have any issues please do not hesitate to contact me.

https://www.surveymonkey.com/r/XMDGZT5

Appendix 2: Survey Questions

<u>Demographics</u>

1. Are you completing this survey from a personal perspective or on behalf of your organisation? Personal perspective, Organisation, Other (please specify) (if 'personal perspective' is answered the survey will move to Q4)

2. What organisation do you work for?

3. What type of organisation do you work for? Academia, Government department, Industry, Insurer, Organisation representing a group within society, Patient organisation, Private health service provider, Professional organisation, Public health service provider, Regulatory agency, Research funder, Trade union, Other (please specify)

4. Are you located in an urban or rural area? Urban, Rural, Other (please specify)

5. Would you be willing to be contacted further for more in-depth feedback on this topic? Yes, No

6. If yes, please provide your contact details. Name, email address, phone number. We may or may not be able to follow up with you.

7. Do you consent for the HRB to retain your contact information linked to your responses on record for the purpose of potential follow up? (Yes, No)

<u>Health Services and Systems Research</u>

8. *Ireland continues to face obstacles in providing good healthcare for the entire population. Health services operate under severe pressures. In order to provide a better health service, operating assumptions need to be investigated.*

In your opinion, what are currently the top 5 priorities for health services and systems research within Ireland and why?

What challenges in the health system do they address?

(If possible, we are looking for a detailed answer response that sets out the particular aspect of an overarching challenge. For example, instead of the question 'why do we see the sky as blue?' we would look for:
How is light scattered in the Earth's atmosphere so that more colours with shorter wavelengths, such as blue, reach our eyes?
Or:

How do the cone cells in the human eye interact with the visual cortex in the brain to construct our perception of colour?

However, we are not looking for specific research projects.)

9. *Some health services and systems research priorities may be unique to Ireland whilst others will have cross border importance.*

For which research priorities do you see added value in organising health services and systems research at European level? Why? Please rank in order of priority

10. *To-Reach presents one of the first examples of developing a structured information exchange between health research funders and health stakeholders. We want to better understand whether particular solutions can be implemented and transferred effectively into other settings.*

What do you believe are the key conditions for the effective and appropriate transfer of healthcare solutions between health systems across different countries?

11. *Ireland has made significant advancements in health services and systems research in the last decade, and at a population level we have seen improvements in health status and other health outcomes. However, there is plenty of scope and opportunity for improvements in both.*

Considering the current state of health services and systems research within Ireland, what do you believe could be done to enable the growth and improved relevance and reach of health services and systems research within Ireland?