Public Health Agency

Research and Development

Review of HSC R&D Infrastructure

Stage 1
Analysis of Results from Survey Monkey
May 2017

One hundred and seventy-one responses were received to the survey though not all respondents completed every question and there were some duplicated responses. Most respondents were either academics or health professionals or both. The remainder held research management or administrative roles, organisational or managerial roles or were service users/public members.

Table 1
Respondents' Main Role

Answer Choices	Responses	
Academic / Researcher	**41%**	43
Health Professional / Clinician	**48%**	51
Research Managerial / Administrator Role	**20%**	21
Organisation Managerial Role (e.g. CEO / Director / Head of Department)	**7%**	7
Industry Representative	**2%**	2
Service User / Carer / Public	**6%**	6
Other (please specify)	**8%**	9
Total Respondents: 106		

Almost two thirds of respondents stated their main organization as a Trust or HSC body. There were disappointing responses from the voluntary sector and industry.

Table2
Respondents' Main Organisation

Answer Choices	Responses	
University/Academia	**39.25%**	42
HSC Trust/Body	**71.03%**	76
Voluntary/Community Organisation	**4.67%**	5
Life Sciences/Industry	**5.61%**	6
Independent/Private Sector	**0.00%**	0
Government/Civil Service	**1.87%**	2
Patient and Public Involvement Group	**8.41%**	9
Other (please specify)	**2.80%**	3
Total Respondents: 107		

The following analysis provides a break-down of responses to the structured questions and a content analysis of responses to the open ended questions. Analysis of the open ended questions across the survey responses showed that several main themes were reiterated in response to questions. These are summarized in Table 3. Extracts from respondents' quotes have been used to highlight these themes. The most frequently mentioned responses related to coordination between different parts of the infrastructure, resources, the focus for funding and the need for a regional R&D centralized function.

Table 3
Themes

Themes	Responses	
Co-ordination/Duplication of roles	**184**	
Resources	**187**	
Regional Function	**121**	
Focus/Disease Driven/Inequalities/Prioritisation	**116**	
Career Development/Capacity Building/R&D Recognition in Trusts	**98**	
Clarity/Communication	**97**	
Awareness	**57**	
Collaboration/Networking	**53**	
Education/Access to support	**41**	
Leadership	**33**	
PPI	**33**	
Knowledge Transfer/Innovation	**25**	
Other	**39**	

The majority of respondents (66%) felt that it was clear what each part of the research infrastructure contributes. However, only a third agreed that organisations within the structure were complimentary with minimal overlap and just over half agreed that each was accessible and responsive with strong leadership.. Analysis of 83 responses to perceived gaps in the structure and organization, related mostly to the lack of coordination between different elements, the perceived duplication of roles and processes between Trusts and the delays this was felt to cause to the research governance process.

Table 4
Structure and Organisation
(N=123)

	Strongly Agree	Agree	Neither agree/disagree	Disagree	Strongly Disagree	Total
It is clear what each organisation in the research infrastructure contributes.	**12%** 14	**44%** 53	**20%** 24	**20%** 24	**5%** 6	**121**
Organisations are complimentary with minimal overlap/repetition and no obvious gaps in terms of the	**5%** 6	**29%** 35	**31%** 37	**27%** 33	**8%** 10	**121**
Each organisation is accessible and responsive with evidence of strong local leadership.	**7%** 8	**45%** 54	**29%** 35	**15%** 18	**5%** 6	**121**
Each organisation endorses and appropriately supports the involvement and participation of service users and public.	**20%** 24	**40%** 48	**31%** 38	**5%** 6	**4%** 5	**121**

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'There is a huge amount of form filling and gatekeeping. The processes for ethical approval and then research governance approval would put off any but the most determined of researchers. Complete disincentive for clinicians and undergrads (and some postgrads) working in health to become involved in research'.

'The majority of the research infrastructure work independently'

'The *system is overly complex and fragmented given the small and uniform structure of health services in NI'*

'There needs to be a radical overhaul of how research governance is operated particularly at Trust level as it is slow and unresponsive. There is no need for five governance offices in NI'.

Some respondents felt that there was a lack of clarity as to the role of each element of the infrastructure, how they linked or who to contact about specific questions within each of the different organisations.

'It is difficult to sometimes identify who is the right person without multiple conversations. There are too many people working in the same space in a small society which dilutes the success for funding applications particularly between the academic institutions.'

'Many parts of the infrastructure appear to work in almost watertight compartments, with   little knowledge of, or cooperation between, the various components. • For many of us, some working here for decades, this is the first time we have seen an organisational chart such as the consultation diagram. Consequently, it is far from easy to navigate the system or contact the right person.'

'Individuals working in the constituent parts are very helpful, but it is not clear who to contact for different queries. Navigating the system seems to require some level of 'insider'   knowledge.'

Unsurprisingly, when asked what changes were required, several respondents mentioned a regional function to streamline processes across the region, thereby improving the capacity and reputation of Northern Ireland as an international research centre, as well as the experience for local researchers attempting to set up research studies.

'If there was some way to streamline governance processes at a Trust level such that NI could be seen as one site with one process, it would make study set-up much easier for local researchers, and NI more attractive to external and commercial research studies.'

'There could be better linkage across the different elements of infrastructure to improve communication and potential overlap. This would increase the potential for applications with   NI researchers to be successful in an international playing field.'

'Single regional approval of research would be single biggest change which would make significant change to NI approval times. Fast track approval for commercially sponsored proposals. Making NI a more favorable location for undertaking research. Single strategic platform for all infrastructure.'

'Better communication between support departments to speed up internal reviews, prioritise workload and reduce timelines. More trials would be awarded this way.'

'Single point of entry for prospective collaborators.'

'Unified direction of travel, one website to overview and a stronger team approach across organisations to have a regional 'brand' to R&D.'

While 60% of respondents strongly agreed or agreed that each organization endorses Personal and Public Involvement, 40% were either non-committal or disagreed or strongly disagreed. Comments highlighted a perceived lack of public engagement in the infrastructure and dedicated resource to promote and implement involvement.

'Although recent PPI initiatives have been excellent (e.g. Ok to Ask), there is a lack of public awareness of the importance of research and how they can find out about current/upcoming studies and how to get involved.'

'While there is strong advocacy for PPI and it's clearly valued and supported by HSC R&D and e.g. NICTN etc, it feels this aspect of research is vulnerable because it requires time and financial investment that is not ring-fenced within the structure, so is dependent on good practice, but PPI is at risk because of competing pressures.'

'There is a gap in engagement between structures and the people affected.'

'Service user and public engagement could be stronger/more active.'

'Public engagement appears to be minimal.'

'There is no meaningful input into R&D agenda at Trust level for service users. Having a couple of PPI members on a research governance committee should not cut it any more.'

Table 5
Collective Working
(N=119)

	Strongly Agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree	Total
The different parts of the research infrastructure in NI work together effectively and with the wider stakeholder community.	**8%** 9	**35%** 41	**34%** 40	**17%** 20	**8%** 9	119
It is easy to navigate the system to identify and access the right person in the right organization to help progress issues and ultimately deliver research in the HSC.	**5%** 6	**28%** 33	**27%** 31	**28%** 33	**11%** 13	**116**
The research infrastructure has a clear, unified direction of travel with evidence of good overarching leadership in place to ensure a collective approach.	**5%** 6	**32%** 37	**31%** 36	**26%** 30	**7%** 8	117

Less than half of respondents (43%) strongly agreed or agreed that the different elements of the infrastructure work effectively together and only a third reported that it was easy to navigate the system. Just over a third thought there was a unified direction of travel with good overarching leadership.

While many of the same themes were reiterated when respondents were asked about the gaps in collective working in relation to coordination, duplication of roles and clarity, several people commented on the absence of effective collaborations and potential networking between disciplines and with and between other external organisations, e.g. the universities.

'*NI has a small platform of researchers either clinical, academic or in industry so additional engagement with organisations …………would be useful to target new researchers and broaden links with engineering, geography and other disciplines who could support health research'*

'*One of the biggest challenges would appear to be effective working with the wider health service, given the capacity issues it is facing.'*

A third of respondents (33%) disagreed or strongly disagreed that there was a unified direction of travel for R&D resulting in competing agendas and a lack of synergy between the different parts of the infrastructure.

'There is no plan, and nobody with executive power to exercise the plan, As such, the institutions represented in the capability map work with little synergy, competing for internal funding rather than synergizing.'

'Strategy has been clearly set out, but no sense of a collective determination to deliver it at pace. This may be an issue of communication as much as one of collective working, but progress is not easily visible.'

'Infrastructure has been developed somewhat in isolation and so sometimes works against each other e.g. movement of a limited cadre of staff to any new, higher banded posts, results in difficulties across peer infrastructure……………In general there is too much protected working at a site level i.e. fiefdom's within legal entities and not enough shared/collaborative working.'

Ways to address these gaps were conversely reported as stronger strategic leadership within and across the organisations and improved collaboration and networking, particularly between organisations which are seen to be competing.

'An overarching body (strategic board) with a clear remit and understanding of how each element of the infrastructure should be working together and address changes in regulations, adoption of trials.'

'A policy/strategy that drives true collaborative working where it is appropriate i.e. accept that our universities have some different interests, but identify areas of commonality and work with HSC to have specific strategy around these to drive collaboration.'

'Is there an opportunity for the heads of each core infrastructure to meet at least annually and look for synergies.'

'On collective working everyone concerned needs to know what is the final purpose. Therefore each must be kept up to speed in all aspects so the final outcome becomes apparent to all equally.'

Table 6
Breadth and Depth
(N=113)

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree	Total
Given the fact that limitations exist (e.g. funding level, HEI support, HSC priorities, and research strengths) the research infrastructure in NI has the appropriate elements to support diverse topics, specialities, professions, types of research, and regions.	**7%** 8	**43 %** 49	**22%** 25	**20%** 23	**7%** 8	113

Half of respondents agreed that the NI infrastructure has the appropriate elements to support adequate breadth and depth of topics, specialties, profession, types of research and regions. However, of 60 respondents who reported gaps, 50% felt these related to a lack of resources in terms of funding, staff, space and access to support.

'Based on comparable organisations in the UK there is an obvious limit to the resources available to support research locally. Fundamental infrastructure such as a Phase 1 Clinical Trials Unit, availability of specialist staff on permanent contracts, and a joint strategy with other Northern Ireland stakeholders is absent. Given the scale of activity within the NICTU and the ongoing demands, additional resource and space is needed in order to create a successful research infrastructure, along with structures (e.g. BRC and/or JRO) to join up the clinical pipeline and delivery more coherently'

'Slow delivery of Life Sciences Strategy has not helped in this regard - potential and capability is certainly there but the impact of chronic underfunding and under resourcing over many years is evident'

Respondents also commented on the breadth of topics, perceiving that there was a lack of clarity in the way

funding was prioritized or that funding was prioritized in certain areas or to specific disciplines at the expense of others.

'We feel there is very much less support for public health, as opposed to clinical research. • It is impossible to understand how the funding is prioritized – which diagnostic areas and clinical questions achieve funding and why?'

'The decision to pursue depth (excellence in research) has been at the cost of breadth and some professional groups have been left behind'

'More transparency is needed on how priorities are decided and where the funding is allocated'

'It would be beneficial if there was a process for identifying and agreeing priority research areas to ensure funding was only allocated to support such Studies. This approach would ensure that PHA R&D Funding was targeted at priority research areas.'

'The financial restrictions unfortunately impact considerably on NI potential for Health and Social Care research, we do well with what we have but that should not be a reason to accept the status quo'

Some respondents complained that funding was prioritized through the particular areas supported by the NICRN groups and that specialties outside these areas or studies which aren't clinical trials were therefore disadvantaged as a result of lack of fit.

'NICRN (for example) needs redesign away from specialty-based system towards a flexible network that can support modern research needs. Current provision reflects a 1980s landscape - not fit for 21st century, and is holding back cross-disciplinary, genomic, and data-driven research'

'The focus is very much on clinical trials - it appears that researchers engaging in any other type of research will receive very little support from the existing research infrastructure'

'Some clinical specialty areas are not covered by the NICRN infrastructure. This reflects in part local clinical research interests/expertise. Occasionally, however, there are high quality national research projects in these areas for which NICRN is unable to offer support'

Some also complained about regional inequalities, with resources being perceived to be prioritized in Belfast to the detriment of other smaller geographical areas and Trusts.

'The infrastructure is there on the whole, but most of the resources are centred in Belfast around that Trust, and more support needs to be given to other Trusts, or at the least to the Western and Northern Trust who have the most experience of working closely.'

'Smaller Trusts outside the BHSCT don't get the same funding support from PHA to support NICRN adopted studies. I agree that this is largely due to the specialities and regional services that the BHSCT can deliver. However I do think that more can be developed to support and encourage more business to these smaller Trusts.'

Predictably, solutions to these gaps were perceived to be more funding to increase resources in Northern Ireland as a whole but also realignment of existing resources to enable wider regional and topic coverage.

'A more comprehensive approach to some parts of the infrastructure such that a broader range of research could be supported would allow the continuing support of areas where NI has a track record and expertise, whilst also allowing the development of new or unsupported areas. NI needs to be seen as a region but more importantly it needs to see itself as a region'.

'Develop comprehensive R&D support structures additional to the existing productive topic structures within a cohesive platform which manages the deployment and movement of staff to deliver regional portfolio. This will make the regions delivery more efficient, reduce risk to delivery via staff reduction issues and will be more complimentary to commercial sectors wider and changing requirements from HSC'.

However, a need was also expressed to invest in more structured mechanisms for identifying research priorities through closer collaborations with HSC and service users.

'Ways for patients to get involved and shape the questions being asked.'

'Funders need to realize the wide benefits of research in innovate healthcare solutions (both in care and efficiency) in the increasingly pressurized NHS environment. The concept of invest to save has not been adequately supported and this is to our detriment, NI has a potentially vibrant research potential but this is unacceptably constrained.'

'I would like to see a Participation and Public Engagement Team with dedicated premises that allow members of the public to become more involved in consultations, budgeting, and determining research agendas. A participation hub, that can effectively bring citizens voices to people in power who make decisions about how our money is spent'

**Table 7
Capacity Building
(N=111)**

	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly Disagree	Total
The research infrastructure in NI builds research capacity (individual and organisational) such that it is an enabler for an effective health and social care research system in NI.	**12%** 13	**38%** 42	**30%** 33	**14%** 16	**6%** 7	111

Twenty percent of respondents disagreed or strongly disagreed that that the infrastructure builds capacity and a third were non-committal**.** Of those who identified gaps, the lack of recognition for R&D by Trusts to enable research time or career development for health and social care staff was a strong theme which carried throughout responses.

'Trusts need to increase capacity by increasing their staffing and encourage more research activity by introducing incentives such as Pas'

'Most researchers in the nhs do this work for free'

'Need improved engagement with Trusts to ensure research is a core value'

'It clearly does, but perhaps support for 'low level' ideas from jobbing clinicians, who may have much to contribute, could lead to small or pilot studies of value'

'My impression is that NHS Trusts have many priorities understandably and research is not one of them / NHS staff are actively discouraged from doing research and the support infrastructure is not adequately resourced'

Difficulties in maintaining a career pathway in research were also identified as a gap in capacity building, as were the lack of opportunities for career progression via funding opportunities provided by R&D within its current schemes*.*

'This lack of an identified pathway for staff development within the infrastructure ensures that expertise is bled from the system and the lack of a clear commitment form the Trusts that R&D is a core function of business leads to disengagement at local level, across all professional groups.'

'Some core disciplines are under-represented in terms of Fellowship support including statistics and health economics. It is my belief that overall, Government in NI should allocate fewer DE funded studentships and offer more support for post doctoral positions.'

'Capacity building for personnel is largely limited to fellowships offered to individuals working in the HSC sector - this needs to be broader in terms of being eligible to non-HSC workers, and also allow for shorter periods of research training (not everyone wants to do a 3 year PhD!).

'Capacity building appears to be just a term but is not followed through in action. For example the Enabling Awards seem to be just another funding stream for experienced researchers, so the successful are being rewarded. That is not really capacity building in any medium to long term sense.'

'Lack of opportunities to get involved, other than as research fellows, and even then, clinical pressures hamper access.'

'HSC Trusts receive a research Directors discretionary allocation of £50k annually to support local research projects. My experience as research director was that it was sometimes difficult to ensure effective and timely spend when funding was allocated to clinical teams'.

Interestingly, changes to address this gap were thought by some respondents to be around clearer career pathways and recognized routes for knowledge transfer as well as key performance indicators for research in Trusts.

'Motivation for the Trusts to support research as a core function i.e. where it is part of normal care pathways. A means whereby best practice/research findings can be shared and discussions held as to when and how to adopt findings across the system'

'Funding for post-doctoral research programmes is a clear area of need and it is argued that if we are serious about building research capacity, dissemination and impact from research, then proportionate funding could be given to post-doctoral fellowships, research sabbaticals, open access licences, research career progression grants and impact grants. • Capacity building should be delivered via a cross-cutting theme for everyone, which is more likely to impact upon capacity to deliver against requirements'

'Funding, trust engagement, recognition that research activity and outcomes should be integral Trust performance measures, otherwise I don't see trusts engaging in a wholly effective manner to support a sustainable infrastructure. The evidence that research activity equates to better clinical outcomes and quality of care is key, we cannot discuss quality without adequately supporting research.'

Overall, 41 responses related to an expressed need for more education or training to increase the capacity of researchers within the system, and better access to support including specialist support provided by statisticians and health economists.

'Time should be allocated for staff learning beyond mandatory training, to allow for development of knowledge. Funding for those wishing to pursue further academic studying.'

'Investment in basic research skills training.'

'More research fellowsips. Protected time over longer term to carry out research, closer links between research and QI i.e. to develop a research-savvy workforce.'

Table 8
Efficiency
(N=110)

	Strongly Agree	Agree	Neither Agree nor	Disagree	Strongly disagree	Total
The system provides appropriate support to researchers and research organisations, to enable efficient approval, design, adoption, set-up and delivery of research studies across the HSC.	**6** 7	**38%** 41	**28%** 30	**21%** 23	**7%** 8	**109**
The guidance and processes for the development, approval and delivery of research are clear, transparent with appropriate 10prioritization.	**6%** 7	**31%** 34	**30%** 32	**6%** 28	**6%** 7	**108**
Each part of the infrastructure responds in a timely manner such that the overall timelines are streamlined and comparable with other parts of the UK and Ireland.	**4.67%** 5	**26.17%** 28	**31.78%** 34	**28.04%** 30	**9.35%** 10	**107**

Less than half of respondents (44%) felt that the system provides appropriate support to enable efficient approval and set up of studies across the HSC and only a third agreed that each part of the infrastructure responded timeously. Again the lack of coordination and duplicated roles and processes between Trusts in particular were strong themes when respondents were asked to identify gaps in efficiency.

'There is significant variability across the 5 trusts in terms of governance approvals, the reasons for this are often unclear to researchers and it creates an inequity of access to research for patients across the province.'

'Lack of responsiveness has been reported as a major issue- in some cases, calls from industry regarding potential collaboration/study participation are simply not returned.'

'Biggest issue relates to governance approval at Trust level.'

However, there was also recognition that lack of capacity and resources impacted on the ability of organisations within the infrastructure to provide adequate support. There was particular mention of the NICTU's and NICRN's facilities to respond to all demands for support, particularly for non RCTs but the resources of Trust research offices were also mentioned.

'*There is under-capacity at the NI Clinical Trials Unit'*

'NICTU is also working at capacity, which means they do not have the resources to support potentially valuable research and need a considerable period to facilitate support. This is not my experience of some other CTUs in England.'

'Studies that were being proposed to the networks are not able to be undertaken due to the lack of staffing to fulfill the commitment required by that study. Consultant medical staff may feel that they are not being supported due to the staffing issues as proposed studies are not starting in a timely manner due to underfunding for staff, therefore medical staff will not be keen to get involved.'

'Again, NI is poorly financed compared with UK. More investment needs to be provided. The research offices have minimal staff and if someone goes off on long term sick leave this creates enormous pressure on the team and creates delays with permissions which is frustrating for the research team.'

When asked what changes might address these problems, the need for a regionalized centralized research

approvals system was also reiterated with a minority mentioning the proposal to move to a proportionate review type system similar to that used by ORECNI..

'Centrally co-ordinated R&D infrastructure support, ideally located in shared office space environment. Maybe move to separate HSC trusts R&D offices being satellite sites, with core R&D infrastructure support being delivered by a central regional service'.

'Re-start afresh with one ICT system, new model of working concentrating on what can be done via a central model and what is best done locally. Better joined up processes and supporting infrastructure for R&D for all!'

'There is an opportunity to formulate a risk based approach to improve efficiency. Within the ethical review system a proportionate approach is taken, which has enhanced the turn-around times of ethical review. However, this is offset by the lengthy period that can be taken within Trusts to undertake the local R&D approvals. This is an opportunity to consider models being used in other settings and apply them, where appropriate to HSC R&D review within Trusts'.

Table 9

Benefits

(N=110)

	Strongly agree	Agree	Neither agree/disagree	Disagree	Strongly disagree	Total
The research infrastructure in NI benefits a wide range of stakeholders including; patients, clients, researchers, research organisations, Trusts, Universities, the life sciences industry, the public and others.	**36%** 39	**44%** 47	**14%** 15	**5%** 5	**2%** 2	108
The research infrastructure in NI is essential in ensuring that high quality, relevant research can take place in the HSC.	**56%** 61	**29%** 32	**11%** 12	**2%** 2	**2%** 2	109

The majority of respondents (80%) strongly agreed or agreed that the research infrastructure benefits a wide range of stakeholders and strongly agreed or agreed (85%) that the infrastructure is essential to ensuring high quality research in the HSC.

Comments from the open ended questions suggested that more needed to be done to raise awareness of the benefits of research and to highlight the work already being done.

'More NOISE needs made about what is done!'

'Need to maximise the benefits of the size and scale of NI'

'Opaque as the structure and help available may be to me, the existence of such research based structures, embedded in clinical worlds, is crucial to the health and wellbeing of NI, never mind for attracting funding and employment!'

'The NI Government MUST realise the importance of Healthcare Research. It is vital that funding into high quality research is an absolute priority to the future of Northern Ireland and to keep some of the brightest and best minds here.'

Not everyone felt that there were benefits to all patients.

'Clinicians perceive little apparent benefit. There may be benefit for some patients such as in oncology but surgical patients do not benefit from involvement in surgical research.'

Conversely some respondents thought efforts should be made to address these gaps through greater visibility of R&D and better efforts to raise awareness of the benefits. Again, a regional service was highlighted by some respondents as a means to raise Northern Ireland's research profile.

'*A Research champion at the Assembly*'.

'*Leaflets, posters*'

'*We tend to be reticent in publicizing research activity to the public and highlighting the key role of research to the public and policy makers*'.

 '*By marketing NI as a single site for research rather than each trust, the benefit to those in the far reaching corners of NI would be greatly improved as there will be the potential of much easier access to available research*'

'*Move to a central hub and spoke design - impact of this would potentially providing single sign off for NI, increased potential for investment from external stakeholders - "NI Plc is a great place to come and deliver high quality research*'

'*Greater signposting for SMEs to the like of C-TRIC to highlight its strength as a vehicle to engage across all of NI*'

In addition and again, effective mechanisms for knowledge transfer were seen also as a way to ensuring the infrastructure resulted in benefits to its wider stakeholders, as were more involvement with the public and greater links with industry.

'*More funding for knowledge transfer projects • Raise the profile of research within the general population and increase accessibility to research*'

 '*It might be a good idea for NI to consider more support for CLARHC - type bodies to enhance and improve translational implementation science*'

 '*Discussion with service user/ carer groups may yield information regarding how this could be best achieved*'