Research
St Andrew's Healthcare

Research Framework

> OUR GUIDING PRINCIPLE IS HOPE – the belief that it is possible for someone to lead a meaningful life, despite serious mental illness

AUTHOR	DATE	VERSION
Johnny Fountain	03 April 2019	**Apr 19**

Contents

1. EXECUTIVE SUMMARY

The purpose of this paper is to set out the framework for research at St Andrew's Healthcare for the next 3-5 years. It is intended to inform the Research Committee in defining the research strategy, whilst ensuring that it is aligned with a vision that supports St Andrew's charitable aims and promotes improved mental and physical health outcomes for patients in a wider context. It will enable the growth of a robust research portfolio and development of key collaborations, for example through the establishment of MOUs and specific project development with academic institutions.

1.1 CONTEXT

Every year, tens of thousands of people with the most severe mental health issues are detained under the Mental Health Act 1983, with many requiring specialist care in a secure hospital environment because of the risks they pose to themselves and others. Mental health research lags behind other areas of medical research, due to lack of funding and prioritisation, leading to a paucity of discoveries and improvements in treatment and care.

1.2 APPROACH

The research framework will focus on three key themes:

1. Personalisation: building a patient-centred knowledge base to change individual care and outcomes
2. Mental and Physical Health: developing treatments for the whole person; exploring the interplay between mental and physical conditions
3. Transition: improving the patients' journey across and between mental and physical health systems and settings

1.3 DELIVERY

The Research Centre staff will provide the administrative and research support and expertise to build and deliver a reputable portfolio of innovative projects. We will nurture and support clinicians to develop their research skills through the provision of expert training and assist them in the development of research ideas, the writing of grant applications, clinical trial design, data collection and statistical analysis. Through our academic collaborations, we will access knowledge and skills to complement our clinical capability; this is anticipated to be in the form of a programme of external studentships/fellowships (MScs and PhDs), with student supervision provided by both the university and St Andrew's.

2. CASE FOR SUPPORT

2.1 CONTEXT IN DETAIL

OUR VISION – for everyone affected by mental ill-health to be able to lead a full and active life in society

The number of people suffering from untreated or under-treated mental illness is growing; yet little is known about preventing, diagnosing or treating it.

Every year, some 63,000[1] people with the most severe mental health issues are detained under the Mental Health Act 1983; of these, over 20,000 require specialist care in a secure hospital environment, because they pose a significant risk to themselves or others.

Treatments are effective for some, but fail many others; we need a new generation of therapies that enable people to overcome mental ill-health. It is now recognised that 'mental illness is the largest single cause of disability', representing 28% of the national disease burden[2]. The human cost is too high and financial burden on society unsustainable – the necessity to address this knowledge gap is clear and urgent.

Mental health research needs to be prioritised, if we are to make similar strides to those improvements in treatment and care for physical health conditions. We know that an increase in spend in targeted areas of research can have a significant impact on patient outcomes; for example, the substantial investment in cancer research has significantly increased the lifespan of people diagnosed with the condition. The same can be achieved in the field of mental health. If we are to shift the current inequalities and deliver a step change in outcomes, such as those achieved in physical conditions, we need to invest in dedicated research programmes.

Whilst there has been an increased focus on fundamental research into early diagnosis and prevention, it will be many years before this research has any impact on the many thousands of people suffering from chronic mental ill-health today. The Research Centre at St Andrew's Healthcare is uniquely positioned to conduct research into Severe Mental Illness (SMI) and translate findings into improved outcomes for patients. It is imperative we develop clinically-based translational research to address the needs of patients and their carers and St Andrew's Healthcare can help to address this gap.

Our research activities will drive innovation and underpin the advancement in psychological, social, cultural and pharmacological support: bringing hope for the future.

2.2   WHY RESEARCH IS IMPORTANT?

The evidence base for what works is often limited in Mental Health. There is a clear need for Mental Health services to focus on using evidence to improve outcomes and reduce variations in care. It is research that will provide the evidence to make a real difference to people's lives and health outcomes. Research ensures that better understanding and support can and will be found. There is no doubt that future innovations in mental health will be driven by research, and investment in this area will ultimately extend the frontiers of care. St Andrew's has the opportunity to lead the way.

Research is needed to:

- Give hope to the 20,000[3] patients detained in secure hospital services, each year; delivering better solutions and preventing long-term institutionalisation.

- Help the thousands of young people at risk of self-harm, suicide or causing harm to others, to safely transition out of secure settings and return to society, as

---

[1] NHS Digital (2016) Inpatients formally detained in hospitals under the Mental Health Act 1983, and patients subject to supervised community treatment; Annual Statistics 2015/16

[2] Annual Report of the Chief Medical Officer 2013(2014) Public Mental Health Priorities: Investing in Evidence.

[3] Inpatients Formally Detained in Hospitals Under the Mental Health Act 1983 and patients subject to Supervised Community Treatment: Available at: http://content.digital.nhs.uk/catalogue/PUB21748

efficiently as possible. Suicide is the leading cause of death in young men and women.[4]

- • Eliminate the adverse health outcomes associated with serious mental illness – such as diabetes, reduced quality of life and lost life years; the life expectancy of people with serious mental illness is 15-20 years less than average.[5]

- • Reduce the number of cases of relapse and crisis after discharge, which have a significant personal, social and monetary cost, contributing to the annual £9.2 billion spent by the NHS on mental health support.[6]

> OUR MISSION – to improve the lives of people who experience severe mental ill-health, through the design and delivery of collaborative, patient-driven research that advances mental health practices, treatments and environments. Our goal is to identify and address the obstacles preventing people from moving to the most appropriate, least restrictive setting – and back into society, wherever possible – in a safe and sustainable way.

3. RESEARCH APPROACH

The overriding principles of research conducted at St Andrew's are that it leads to changes in clinical practice or policy, is innovative and patient-centred.

We aim to be an early adopter of innovative technologies and therapies, and so will prioritise research that can be translated into clinical practice. St Andrew's provides specialist clinical services to a large cohort of patients with complex mental health problems and this patient group will define our approach. St Andrew's also combines significant clinical expertise with specialist services and facilities, we will build on these assets to create distinct research portfolio.

The research focus will be serious mental illness in those people residing within a secure mental health setting and how their post-discharge recovery correlates to, and can be improved by, the treatment they received in this environment. This will help to change clinical practice, accelerate changes to service models and bring wider societal and economic benefits.

3.1 THEMES

The research framework is focussed on three themes:

1. Personalisation
2. Mental and Physical Health
3. Transition

3.1.1 Personalisation

Personalisation refers to increasingly sophisticated bespoke care planning, rather than generic solutions for similar diagnoses or clinical presentations. It identifies the patient and their needs, and shared decision making between patient and clinician as paramount.

---

[4] NHS England. "The Five Year Forward View for Mental Health: A report from the independent Mental Health Taskforce to the NHS in England" February 2016

[5] Wahlbeck,K, Westman, J, Nordentoft, M,Gissler,M,& Laursen, TM, (2011) Outcomes of Nordic patients with mental health systems:Life expectancy of patients with mental disorders. *British Journal of Psychiatry*, 199(6), 453-458

[6] NHS England. "The Five Year Forward View for Mental Health: A report from the independent Mental Health Taskforce to the NHS in England" February 2016

Data-driven research has potential to impact on the timing, delivery and type of treatment an individual receives – for example, changes in length of stay, changes to prescribing practices and introduction of innovative therapies. We aim to increase patient choice, enable people to take control of their own recovery journey, and increase the prospects for everyone affected by mental ill-health to be able to lead a full and active life in society.

3.1.2 Mental and physical health

It is well known that mental and physical health are fundamentally linked.[7] Parity of esteem in a healthcare context is usually understood to be valuing mental health equally with physical health. However, within a mental healthcare setting, the tendency can be to overlook physical health because of the understandable focus on mental health. This theme aims to give equal weight to research into physical health and its links to chronic mental health conditions.

People with mental health problems have a reduced life expectancy and are at increased risk of developing severe physical health problems, including cancer and heart disease. Poor physical health is a major inhibitor to mental health recovery and can lead to stigmatisation, isolation and depression. Those with severe mental illness are more likely to experience some of the most severe health inequalities, dying on average between 10 and 25 years earlier than the rest of the population.

Research offers an opportunity to investigate and develop novel treatments for the physical disorders experienced by people with mental health problems, enabling integrated mental and physical health care and treatment that prevents adverse health outcomes, including physical disability, lost life years and reduced quality of life.

3.1.3 Transition

The purpose of this research theme is to ensure that people using inpatient mental health services, and their families and carers, are better prepared for, and have a better experience of, moving between different settings (for example, between their home, secure hospital or other community settings).

Poor transition can be detrimental for physical and mental health outcomes, and expensive for society. Of particular concern are: the transition from child and adolescent services to adult services, and the institutionalisation of longer stay adult inpatients, which can inhibit successful integration into a community setting. Research within this theme is aimed at preventing potential relapse and the 'revolving door' of care, which has a huge personal, social and monetary cost to society.

3.2 KEY STRANDS

3.2.1 Technology-enabled care

An increasing proportion of technology-enabled care research and service evolution is targeting the transformation of health and care services through emergent, digital technologies, including simple social alarms, telecare, and digital and mobile apps for the self-management of health.

---

[7] A 2012 report, by The King's Fund, suggests that at least 30% of people with a long-term physical condition have a mental health problem and 46% of people with a mental health problem have a long-term physical condition: "Long term conditions and mental health-the cost of co-morbidities" (2012).,England:

The telecare segment already delivers services that directly support the independence and safety of over 1.7 million vulnerable people[8], though their use remains limited in people with serious mental illness.

Though there are undoubtedly issues surrounding the usability of devices, and the validity, reliability and privacy of the data need to be resolved, the move to technology-enabled care and assessment offers us the ability to: collect physiological and self-report data; create scalable services; design predictive services; and support patient self-management and communication with clinicians.

3.2.2 Digital health

The digital health revolution brings significant potential for data-driven research and delivers untapped opportunity to reveal new knowledge through the analysis of aggregated data sets, across multiple parameters. This approach will expose patterns and anomalies that will inform further research questions and deliver more immediate translation into practice – for example, cross referencing care plans and outcomes with physiological data could well raise basic research questions, whilst immediately providing evidence that impacts on an individual's treatment.

A key tool to achieve these aims will be the development of a Patient Data Registry – a tool through which St Andrew's clinical records databases and electronic prescribing records can be aligned and interrogated. The detailed analysis of existing data can be used to develop more accurate personalised care plans, to provide more targeted therapies. The Patient Data Registry will serve as a platform for a significant expansion of our research capacity and will serve as a key facilitator for the development of external research collaborations.

3.3 DELIVERY

3.3.1 Horizon scanning and innovation

Using a continual horizon scanning approach, in combination with ongoing discussions with our clinical staff and external researchers, we will identify key technology and digital health projects that are most likely to have significant impact, in the short to medium term (5-10 years). The aim will be to build expertise in these areas and identify collaborative partners and external funding sources to support a portfolio of innovative projects.

3.3.2 Growing our own talent

Research will have its greatest impact where we have clinical expertise and can determine which research questions are most relevant to our patients. We must build a culture at St Andrew's where translational research is part of everyday clinical practice. Ultimately, we want 'research' to be a natural part of the care conversation. To achieve this, we need to develop an infrastructure and opportunities that will support researchers from within the charity.

3.3.3 Collaboration

The services and facilities at St Andrew's are not routinely available to the NHS, making collaboration a potential opportunity for funding. Furthermore, St Andrew's hospitals bring key assets, such as infrastructure for data collection in collaboration with local access to general NHS hospital services – all of which make St Andrew's hospitals an important research partner. Active collaborations with universities ensure that our research is informed

---

[8] Telecare Services Association."Connecting People, Improving Lives: A Digital Future for TEC" (2017)

by the latest academic thinking and, by partnering researcher, clinician and patient, we can achieve meaningful projects with maximum impact. Collaboration with academia and the NHS will also, importantly, open access to statutory funding streams and larger multi-site projects.

3.3.4 Patient and Public Involvement (PPI)

There is, in general terms, strong support amongst patients and carers for research as the best way to find cures, to improve care and treatment, to improve patients' quality and length of life, and to prevent illness. However, research does not always address the things patients think most important. It is important that researchers take patient and carer perspectives into account, when they are planning their studies. Co-production helps medical researchers understand what outcomes matter most to patients and allows wasteful or unnecessary research plans to be challenged.

Family, carers, clinicians and patients at St Andrew's have co-produced a framework which outlines nine specific outcomes, mapped to three priority outcome areas of personalisation, mental health and physical health (Figure 1).

Figure 1   Patient defined outcomes

Key patient outcomes			Specific outcomes
Personalisation	Preventing institutionalisation & dehumanisation & promoting personalised care	P1	People feel included in society & are treated fairly
		P2	People receive person-centred care, support & treatment
		P3	Family & carers are informed & confident in caring
Mental Health	Preventing poor mental health, reducing risk to self & others	MH1	People have improved understanding of their mental health
		MH2	People safely live the life they want to live, managing risks to self & others
		MH3	People have purpose in life & independence
Physical Health	Enhancing physical health & preventing early death from physical conditions	PH1	People live well with their physical health conditions
		PH2	People live a healthier life and make healthier choices
		PH3	People receive the best physical healthcare

Upon publication in early 2017, the identified outcomes were incorporated into the assessment of new research proposals at St Andrew's and will inform the development of the our research portfolio.
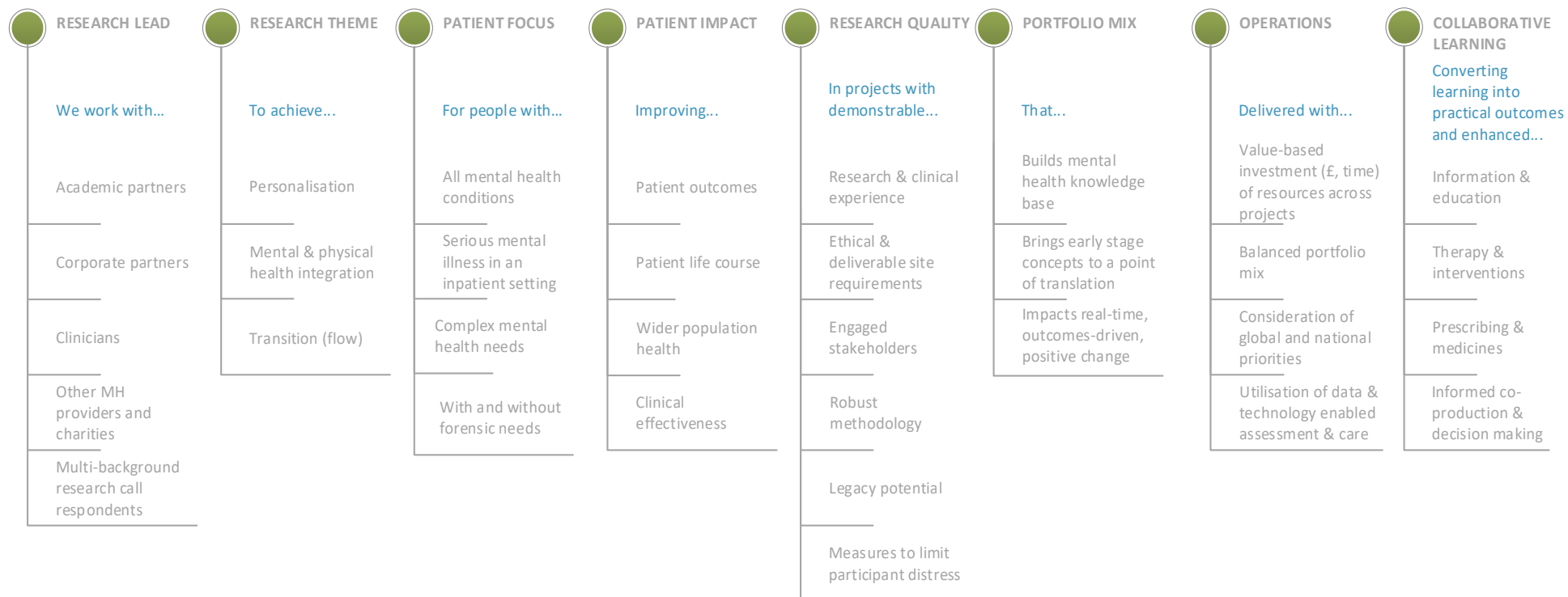
3.3.5 The Research Centre

The Research Centre drives the research agenda in addition to providing a broad range of expert research support. This includes giving advice on protocol development and project management (for larger projects), ensuring good governance, the development of procedures and providing advice on research ethics applications.

This in-house expertise will foster research skills amongst clinicians and assist on the development of ideas, the writing of grant applications, data collection and statistical analysis. Through our academic collaborations we will access knowledge and skills to complement our clinical capability. We will offer a range of pilot and early stage projects for MSc students to participate and work with academic partners to identify and appoint PhD students, with joint academic-clinical supervision, to take larger projects forward.

3.3.6 Research selection criteria

There are key decision points for assessing the value and fit of research proposals to our defined approach (see Figure 2). It is proposed that research encompasses, but is not restricted to, the mental health patient population represented at St Andrew's. The current research portfolio is being reviewed against the strategy and the research selection criteria proposed.

Figure 2   *Research Selection Criteria*

RESEARCH LEAD

We work with…

Academic partners

Corporate partners

Clinicians

Other MH providers and charities

Multi-background research call respondents

RESEARCH THEME

To achieve…

Personalisation

Mental & physical health integration

Transition (flow)

PATIENT FOCUS

For people with…

All mental health conditions

Serious mental illness in an inpatient setting

Complex mental health needs

With and without forensic needs

PATIENT IMPACT

Improving…

Patient outcomes

Patient life course

Wider population health

Clinical effectiveness

RESEARCH QUALITY

In projects with demonstrable…

Research & clinical experience

Ethical & deliverable site requirements

Engaged stakeholders

Robust methodology

Legacy potential

Measures to limit participant distress

PORTFOLIO MIX

That…

Builds mental health knowledge base

Brings early stage concepts to a point of translation

Impacts real-time, outcomes-driven, positive change

OPERATIONS

Delivered with…

Value-based investment (£, time) of resources across projects

Balanced portfolio mix

Consideration of global and national priorities

Utilisation of data & technology enabled assessment & care

COLLABORATIVE LEARNING

Converting learning into practical outcomes and enhanced…

Information & education

Therapy & interventions

Prescribing & medicines

Informed co-production & decision making

3.4   IMPACT

The Research Centre proposes to avoid unnecessary overlaps with those aspects of research that are already funded and ensure focus on those areas where our studies offer significant and credible contributions to the mental health knowledge base. High quality patient data, ranging from genomics through to healthcare service engagement and life experiences, is vital to research intended to improve scientific knowledge in mental health.

3.4.1   Basic research: new ideas

Basic research – research that generates new ideas, principles, and theories, but which may not be immediately utilised – will not dominate the portfolio initially, and will likely involve only 10% of research resources, it will however play a vital role in the development of future research themes such as core research into causes, prevention and diagnosis of mental health conditions, as well as post-discharge services.

3.4.2   Translational research: idea to implementation

This refers to the process of taking projects that are at early concept stage and progressing them to clinical implementation. We will engage and support the development of research proposals that align with our research themes, particularly in relation to new therapies and rehabilitation. This will consume considerable resource, potentially 30% of research commitments.

3.4.3   Translational research: establishing efficacy and effectiveness

This research will identify and trial therapies, methods and technologies that have been consistently associated with beneficial patient outcomes. We will evidence effectiveness and embed them in a real-world environment. It is anticipated that this research will dominate 60% of our efforts in early years. St Andrew's large cohort of patients provides a capability to prove and adopt new care processes, innovatively exploit data, IT infrastructure and potentially service delivery skill sets.

3.4.4   Dissemination

To help change clinical practice for the benefit of patients and society, we will actively disseminate knowledge freely and widely through the publication (Open Access) of research findings and through public engagement. We will produce an annual impact report outlining our results against KPIs and detailing where research has added value to St Andrew's from a patient, clinical, academic and PR perspective.

4. FINANCIALS

4.1   CORE FUNDING

Core funding for the Research Centre will be provided by St Andrew's within the framework of the annual budget round.

4.2   FUNDRAISING

The Research Centre will actively pursue a fundraising strategy to support the research portfolio with the ultimate expectation that the portfolio will be externally funded through a complement of fundraising activities. Key activities will include:

- Statutory grants – public money distributed by the government, through a variety of routes, usually in the form of grants, but also now often under a contract
- Trusts and Foundations – charitable institutions that to award grants against set criteria
- Philanthropic donations – individuals capable of making significant gifts
- Corporate sponsorship – through commercial collaborations to develop products and services or altruistic intent
- Legacies – a gift, either a fixed sum of money, or part/all of an estate, left by a person in their will.

5.   OPERATIONAL MANAGEMENT AND OVERSIGHT

5.1   MANAGEMENT

The day-to-day management of the Research Centre is carried out by a director and a team of five, based at Cliftonville House.

5.2   OVERSIGHT

A Research Committee will provide transparency and draw on external expertise including patient and carer insight. The Committee will assist in setting the research strategy and priorities.

6.   WHAT WILL SUCCESS LOOK LIKE?

6.1   FIVE-YEAR VISION

The Research Centre's five-year vision is for our research portfolio to provide the evidence required to underpin change and evolution in clinical practice for the treatment of serious mental illness, with the purpose of measurably improving patient outcomes and the transition of patients to the least restrictive setting.

We have aligned our strategic objectives with the Charity's top-level priorities, and, importantly, designed them to: reflect the important role technology and data will play in future mental healthcare developments; support our clinicians and embed research in the St Andrew's culture, making it a natural part of the care conversation; foster high-quality, innovative, translational research that is co-produced with patients, delivered through strategic external collaborations and attractive to funders.

Meeting these objectives will ensure we are seen as a 'thought-leader' and place us at the forefront of clinical practice and care model development; enhancing our national reputation and increasing our ability to influence change and impact the development of mental health policy.

6.2 STRATEGIC OBJECTIVES AND KEY PERFORMANCE INDICATORS (KPIS)

Strategic objective	KPI	Linked top-level Charity strategy for innovation and research
To enable our clinicians to conduct high-quality translational research that supports evidence-based change in clinical practice	- MSc placements matched to clinician projects - New guidelines/therapies implemented - Projects supported through seed corn funding	**Future state:** St Andrew's is at the forefront of clinical practice, care modelling and service delivery for patients with serious mental illness **Objective:** Collaborative, patient - driven research will be designed and delivered that advances mental health practices, treatments and environments **Measurement:** • A portfolio of strategically aligned, innovative research in mental disorders in place utilising technology, data analytics and digital health • The Charity is partnering with research partners and funders across academia, the NHS and industry • New statutory and philanthropic funding streams are developed
To evidence the success of value-based healthcare	- Assessment of the validity of the clinical outcome measures within IPUs starting in year 2	
To target funding sources and opportunities, appropriate to our key strands (technology-enabled care, digital health), through horizon scanning, network development, exploitation of existing partnerships and relationship-building with funders	- Development of application for external funding - New Memorandum of Understanding - Grants/funding contributions (£ targets)	
To produce high-quality, innovative research that is attractive to funders, through the targeting of collaborators (across academia, NHS, industry) who have the potential to deliver projects within our key strands	- Peer-reviewed publications and poster presentations of research results at conferences - Co-funded PhDs for strategic projects - New Memorandum of Understandings	
To promote systems and infrastructure that enables us to design and support data-driven projects that maximise the value and impact of our data, in order to deliver step changes in care planning and treatment	- Data registry establishment - Development of procedures for data extraction including good practice guidelines - Internal and external data requests	