

Impact of the All Wales Research and Development Delivery Funding Model

SECTION 1. WHAT ACTION IS THE WELSH GOVERNMENT CONSIDERING AND WHY?

Background to developing the all-Wales Research and Development Delivery Funding Model

Health and Care Research Wales is a networked organisation, supported by Welsh Government, which brings together a wide range of partners across the NHS in Wales, universities and research institutions, local authorities, and others. It has a remit to stimulate research excellence, build capacity and capability, and support research delivery in translational and applied health and care research. This covers translational bio-medical research, through to clinical trials to service organisation and delivery, population and public health, social care and wellbeing.

Health and Care Research Wales supports health and social care organisations, and HEIs, through providing funding for research infrastructure and administering competitive schemes. The budget for Health and Care Research Wales is approximately £42m a year of which approximately £15m is distributed directly to NHS organisations to support and deliver commercial and non-commercial research.

In 2012/13, Health and Care Research Wales (via its predecessor organisation – National Institute for Social Care and Health Research - NISCHR) introduced a new NHS Research and Development (R&D) funding formula called ‘Activity Based Funding’ (ABF) - a model predicated on an assumption that NHS organisations that are more research active in previous years will be more research active in the following year. Through using a fixed budget each year, the model therefore used retrospective research activity as a proxy for future research support needs. The ABF model was introduced at a time when greater clarity was needed on how the NHS R&D funding was allocated to NHS organisations and it enabled NHS organisations to receive ring-fenced funding for research from Welsh Government, report on its use, without it being mixed up with service funding - which historically had been the case.

Up until April 2019, the ABF model had been in place for seven years and whilst it had supported raising the profile of research in the NHS and facilitated the delivery of a wide range of studies across disease areas and healthcare service improvements in primary (including dental, optometry, community) and secondary care, discussions with stakeholders highlighted that improvements could be made.

A series of engagement sessions and briefing events particularly highlighted the need for a funding approach to be: more agile and responsive to the need to support current research underway and align to future research; drive greater collaboration between NHS organisations to open studies over multiple sites for patient benefit, and overcome the challenges of undertaking small sample size studies in areas such as paediatrics and novel therapies.

In April 2019, Health and Care Research Wales commissioned a Task and Finish Group to review the ABF model and put forward recommendations to address the limitations. A set of recommendations developed by an all-Wales research delivery funding model task and finish group were submitted to Welsh Government and proposed a move away from ABF to a model supporting a ‘needs based approach’ whereby funding follows the actual costs required to deliver (or support the delivery of)

research when and where those costs are incurred and not based on a formula. The recommendations for a new all-Wales research delivery funding model were accepted by Health and Care Research Wales in November 2019 and were developed to reflect the five ways of working in the Well-being of Future Generations (Wales) Act 2015.

Long term

The recommendations for a new all-Wales research delivery funding model facilitates the increased opportunities for people in Wales to join health and care research studies. This aligns with the *Health and Care Research Wales strategy* and its remit to support and fund research across the life-course.

Prevention

There is a growing evidence base that research active organisations provide better care and have better patient and public outcomes than those NHS organisations that undertake less research. As well as the benefits conferred to patients, research generates evidence which ultimately transforms practice. As a result, research should be embedded within the clinical care pathway and considered alongside other treatment options.

Integration

The recommendations for the new all-Wales research delivery funding model have been considered alongside *Prosperity for All: The National Strategy for Wales*, and aligns closely to one of its key themes 'Healthy and Active'. The recommendations will foster increased collaborative working across NHS organisational boundaries to deliver real improvements in health and well-being for the population of Wales through facilitating developing a broader portfolio of research that affords the public and patients real and increased opportunities to participate in research studies.

Collaboration & Involvement

The recommendations have been developed by the all-Wales research and delivery funding model task and finish group working in collaboration with key stakeholders (from the NHS and HEIs), who were invited to help shape the recommendations at two key stages via briefing and discussion events. There have also been focused meetings on the developments at the all wales R&D Directors group (known as NHS Support and Delivery Collaboration Group). Other relevant stakeholders include NHS Research and Development staff, clinical leads responsible for research by diseases/themes known as 'Specialty Leads', staff who assist in trial methodology based in Clinical Trials Units in HEIs and research staff responsible for delivering and supporting the research.

Impact

The all-Wales research delivery funding model task and finish group developed recommendations based on an options appraisal that reflect the principles of value based healthcare; that is to achieve high value from delivering the best possible outcome for patients and public in the most efficient way. The outcomes that matter are:

- Opportunities to take part in research are available to the population rather than driven through process measures or targets. This will allow more people to receive the best care or experience new services, or make a contribution to healthcare improvements, through

research. This will include those participating in research by virtue of their health or social care needs, or their use of health or social care services, or as healthy members of the population.

- Investment is allocated and determined to create the maximum value out of the resource available to support high quality research.
- Engagement should involve those who deliver the research and those involved in studies themselves (through study set-up or by participation in a study) to be more closely involved in value based decision making. Allowing all to participate in resource allocation or addressing a particular need will incentivise and drive value (particularly in the context of a fixed budget).
- Good quality information is used to make informed decisions and undertake cost evaluation to assess value. As part of implementation, collecting information that drives best outcomes (e.g. recruitment planned, efficient study set up) will be key.

The new approach will better facilitate studies opening across multiple NHS organisations through ensuring the resources needed will be provided to those relevant organisations.

Costs and Savings

Health and Care Research Wales will continue to manage the existing funding for NHS research. The new proposed funding model is about the way the funding is distributed rather than around savings. It is however anticipated that the new model will maximise the use of funding, as the funding will directly support the research activity involved in live studies underway rather than be allocated to NHS organisations based on historical study data from previous financial years.

Mechanism

No legislation is proposed.

CHILDREN'S RIGHTS IMPACT ASSESSMENT – ALL WALES RESEARCH AND DEVELOPMENT DELIVERY FUNDING MODEL

Describe and explain the impact of the proposal on children and young people

Health and Care Research Wales recognise the opportunities and challenges with undertaking research involving children including clinical trials in complex NHS treatment settings as well as within sensitive social care environments.

In order to stimulate children's research in Wales and to ensure children are afforded increased opportunities to participate in health and social care research studies, Health and Care Research Wales fund specialty leads across a range of disease or thematic areas who are tasked to build connections with other researchers across the NHS and UK, and support setting up studies across Wales. A research Specialty Lead for children has been funded to champion paediatric research across the NHS, stimulating interest in uptake of research and bringing paediatric research studies to Wales thereby ensuring that children in Wales have the opportunity to participate in local, national and international research.

Historically child health research has not fared well in the NHS research funding environment which as a consequence has led to many interventions, medicines and treatments for children lacking the evidence base when compared with adults.

One of the key criticisms of the previous NHS R&D funding model (known as the Activity Based Funding model) was that it did not differentiate sensitively enough between studies that were easier to deliver compared with those that more complex and require more extensive resource - which can be reflective of many research trials involving children.

Throughout 2019, Health and Care Research Wales undertook extensive consultation on the limitations of the previous funding approach, and based on feedback received recognised that a funding approach needed to be: more agile and responsive to the need to support current research underway and align to future research; drive greater collaboration between NHS organisations to open studies over multiple sites for patient benefit, and overcome the challenges of undertaking small sample size studies in areas such as paediatrics and novel therapies. The implementation of the new all-Wales research delivery funding model means that funding follows the actual costs required to deliver (or support the delivery of) research when and where those costs are incurred. It will therefore provide greater agility within the system to ensure that NHS research support funding moves to where the research is taking place and aligned to population health needs. For instance, when researchers make decisions to undertake studies including those involving children, study teams can plan ahead aware that resource will be made available based on actual research activity need rather than the previous approach (where researchers may have needed to seek a slice of the NHS R&D funding allocated to NHS organisations which had been determined by a formula driven by historical research data).

Additionally, over the period of these developments, Health and Care Research Wales has made increased investments in children's research in its 2020 – 2025 infrastructure funding through research centres such as Children Social Care Research and Development Centre (CASCADE) Partnership, Centre for Development, Evaluation, Complexity and Implementation in Public Health Improvement (DECIPHer) and the National Centre for Population Health and Wellbeing Research.

Children and young people have not been consulted within the development of the recommendations for a new research delivery funding model, however relevant researchers and their respective teams (including the specialty lead for children) were engaged in the development process to ensure that the impact of the changes would benefit research involving children.

Explain how the proposal is likely to impact on children's rights

Health and Care Research Wales' mission is to promote, support and provide collective oversight of health and social care research in Wales to ensure it is of the highest international scientific quality, is relevant to the needs and challenges of health and care in Wales, and makes a difference to policy and practice in ways that improve the lives of patients, people and communities in Wales. This vision contributes directly to children's UNCRC rights. The recommendations developed by the all-Wales research delivery funding model task and finish Group have given due regard to how these recommendations will benefit children and young people and have been mindful of The Rights of Children and Young Persons (Wales) Measure 2011.

The articles most relevant are:-

Article 3 – All organisations concerned with children should work towards what is best for each child

Article 6 - All children have the right of life. Governments should ensure that children survive and develop

Article 23 - Children who have any kind of disability should have special care and support so that they can lead full and independent lives.

Article 24 - Children have the right to good quality health care and to clean water, nutritious food and a clean environment so that they will stay healthy. Rich countries should help poorer countries achieve this.