



**Response to Health and Care Research Wales:
NHS R&D Framework
Research Matters
What Excellence Looks Like in NHS Wales**

**Consultation Response
May 2023**

Tenovus Cancer Care is one of Wales's leading cancer charities, with a long and distinguished history of providing practical and emotional support to everyone affected by cancer in their community.

We are committed to working alongside people affected by cancer to champion their needs, raise awareness of the issues faced and ultimately improve cancer outcomes.

With a long history of support for cancer research in Wales we welcome the opportunity to respond to the NHS Research and Development framework being produced by Health and Care Research Wales.

We want to ensure that the outputs from research and innovation improve cancer outcomes in a timely manner and that people affected by cancer are involved in the design and delivery of research from an early stage.

General comments

We regret the short consultation window open for comments concerning the framework. It has limited our ability to engage with the wider All-Wales Cancer Community (AWCC) for their thoughts as people affected by cancer – who may have an interest in the cancer research of the future.

That said, given the fundamental importance of research to health and care, we welcome the framework and the attempt by the document drafters to define what "research excellence" looks like.

However, we are concerned that the framework neglects to reference the key role played by the third sector in the ongoing delivery of health and care research. With the exception of a few large health charities and foundations that are capable of

investing in research infrastructure, the third sector helps to keep research grounded and in touch with the public it serves whether through small/medium sized grant funding; assistance with prioritising activity, or more broad-brush support for innovation and research (against more conventional health and care activity) in discussions with Welsh Government and other Wales institutions.

The nature of research and academic inquiry, across multiple institutions and organisations, and over period of time can act against the needs of the people with health and care needs unless it is translated into health and care settings in a co-ordinated, timely manner. The NHS's Duty of Quality should also, at least in theory, help with driving and trialling innovation, and applying into wider practice the outputs that are proven to work.

“Why should research matter to the Welsh population and to the NHS?”

We agree with the statements in the box underneath the statement *Why should research matter to the Welsh population and to the NHS?*

The “supportive organisations” referred to in the third statement would include third sector charities such as Tenovus Cancer Care, which continues to support the research community in Wales, especially facilitating patient and public involvement

We would add within the fifth statement that research attracts additional income from non-commercial/non-profit driven funders, such as charities acting on behalf of their beneficiaries.

“Who is his document for?”

We suggest that the document also serves a purpose for those scrutinising the design and delivery of research across the NHS in Wales by setting out and defining research excellence. This framework provides the 10 pillars against which NHS delivery of R&D can be compared against.

The 10 Pillars

We would like to see greater recognition of the role played by the third sector across particular “pillars”. By not doing so the framework does not acknowledge the rich pool of talent, ideas and support outside the NHS that nevertheless supports the mission and values the NHS stands for.

We could envisage reference to the third sector within at least 5 of the 10 pillars - *Partnership and Collaboration; Finance; Public Involvement and Participation; Communication and Engagement; and Research Impact* sections.

Those 5 are all areas of work where the third sector can add value to the NHS R&D activity – often through the activity and resources already developed and deployable. For example, [the Tenovus Cancer Care All-Wales Cancer Community](#) adds value to

the work researcher organisations and researchers themselves carry out to access and engage with people affected by cancer. Research opportunities can be shared via a single point of contact to a growing community of people with a cancer experience who want to contribute to better cancer outcomes.

We are interested in understanding how initiatives such as the AWCC can better support NHS research activity. HCRW and NHS partners can and should utilise the AWCC, and other third sector PPI to share condition specific opportunities. We don't have the infrastructure to support researchers in the way the HCRW are able to do, but we do have access to a large "switched on" patient cohort, as do many other organisations in the 3rd sector.

Including within the framework prompts concerning the third sector specifically, or anything about scanning and understanding the wider external environment, would contribute to engagement with individual charities or the coalitions/alliances and partnerships we regularly participate in and contribute to.