

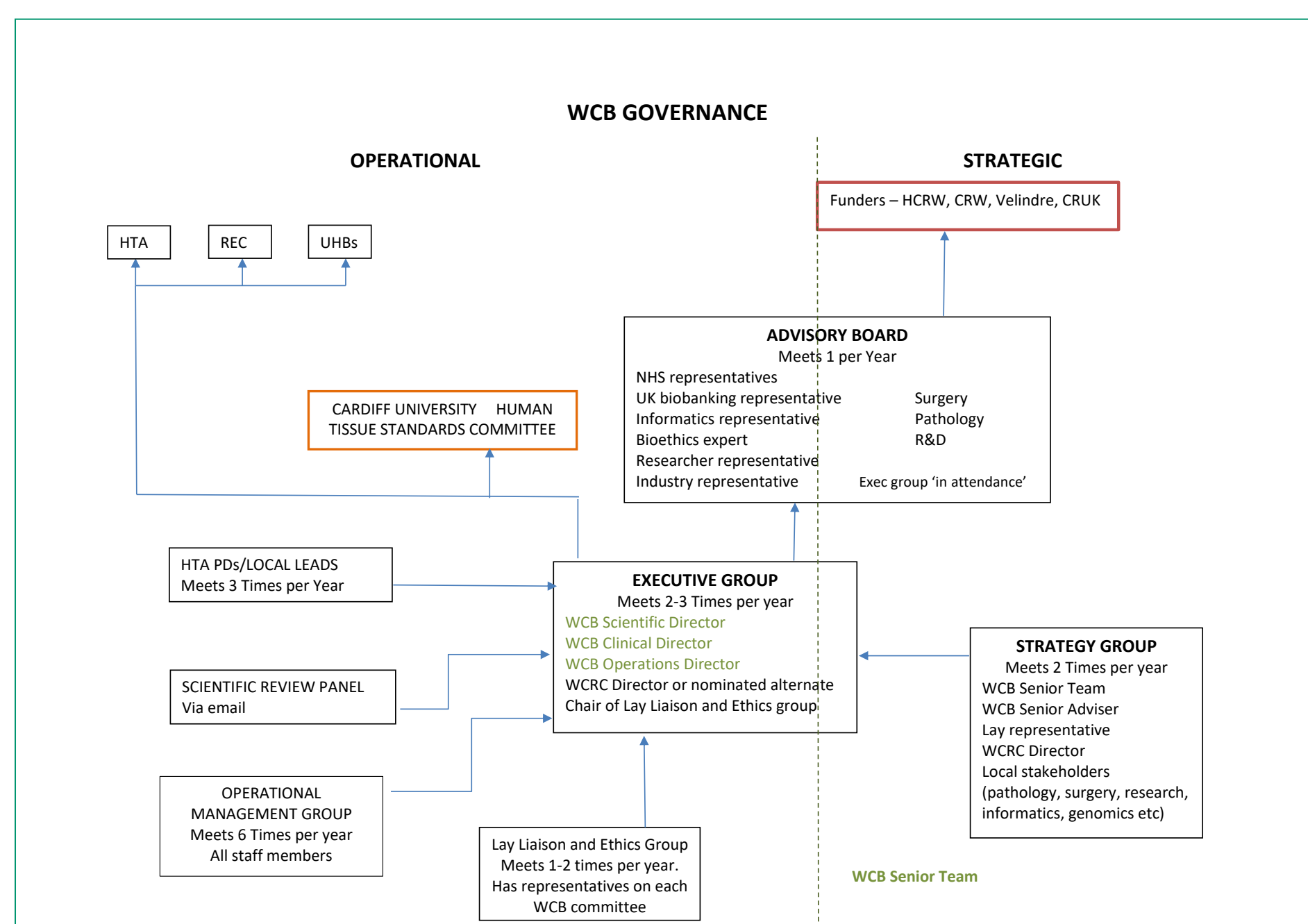
ENHANCED LAY INVOLVEMENT FOR IMPROVED BIOBANKING

Background

The Wales Cancer Biobank (WCB) has involved the public and patients since its inception in 2004. Four lay representatives sat on the original Steering committee to define the biobank. These four individuals formed the nucleus of the Lay Liaison and Ethics group who worked with the biobank senior team to draft the patient information sheet, consent form and the application to the ethics board. This group continued to meet as a distinct group for 15 years and although the Chair of the lay group was a member of the Executive group, other lay members had little to no direct input and contact with the wider biobank staff and management. To improve engagement, involvement and governance, a radical rethink and overhaul of lay contribution was needed.

What did we do?

In 2020 the way the lay group interacted with the biobank changed considerably and members of the lay group were introduced to each of the biobank working committees. In this new structure, two members joined the Operational Management group, and one member joined the Strategy group, whilst retaining the Chair's involvement in both the Executive and Advisory groups.



The group also continues to meet as a distinct committee but the integration into the core groups allows a more informed participation.

Members of the WCB's Lay group are involved in multiple areas of the biobank. They:

- review lay summaries to ensure plain English is used in all applications for use of biomaterials and/or data-
 - applications will not be approved until a lay member is satisfied that the lay summary is suitable,
- work with the biobank to consult on new initiatives,
- advise on amendments to ethics and
- give their lived experiences.

As full members of the committees, lay members receive all the papers and reports and are encouraged to participate equally in meetings.

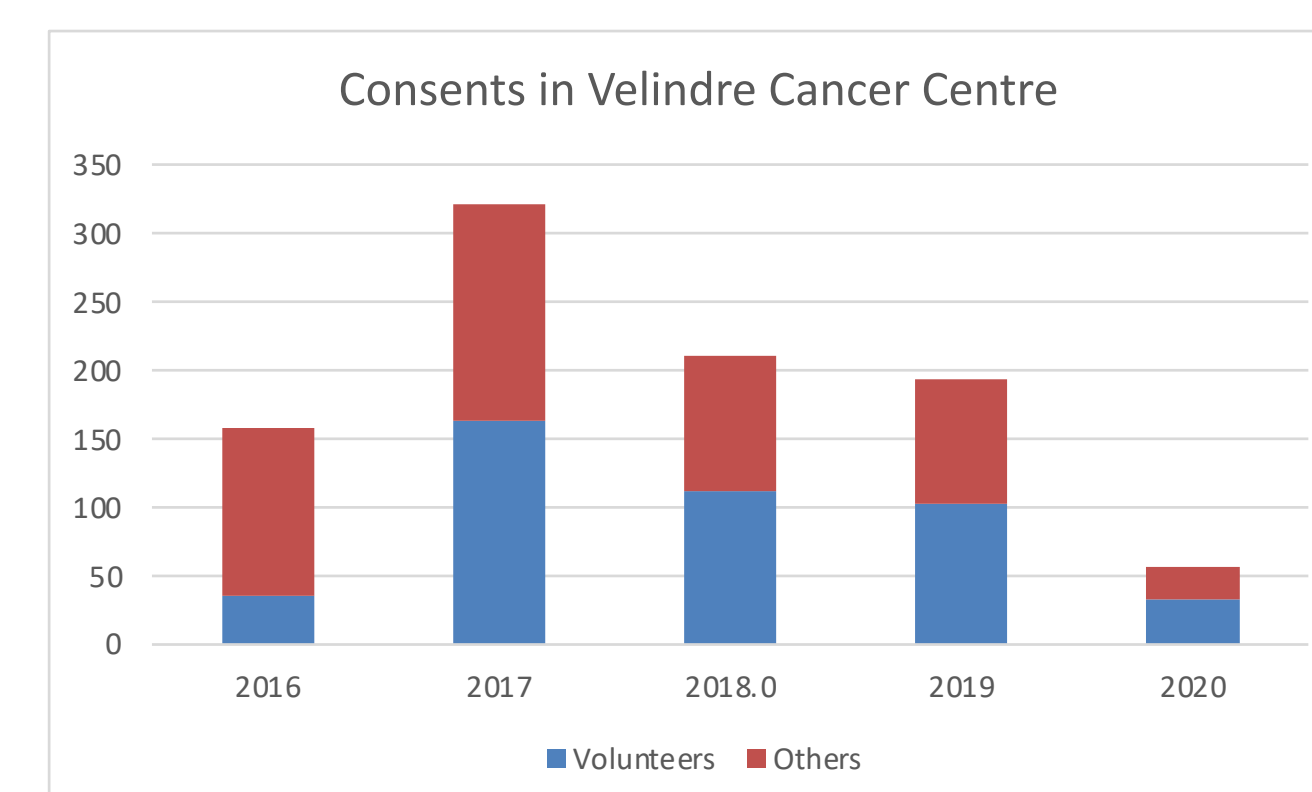
Programme

The UK NIHR National Standards for Public involvement in Research are the foundation of public involvement in the UK.



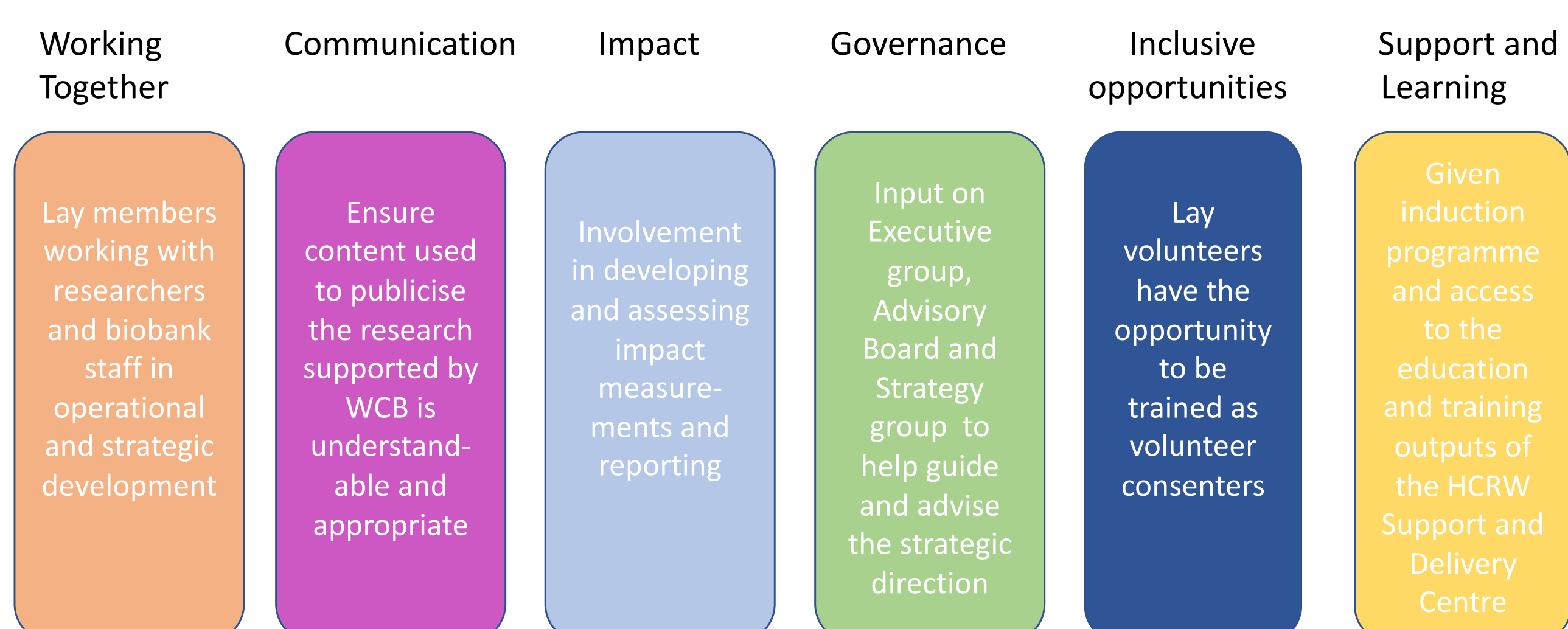
The newly integrated programme maps activity onto the standards, alongside a volunteer consenting initiative* that was instigated in 2016 where members of the public/lay volunteers are trained to speak to donors to ask for consent for biobanking. The volunteers had no direct experience but had a wealth of transferable skills from previous employment.

A pilot project has been running successfully in Velindre Cancer Centre and until the initiative was suspended due to COVID19, the volunteers accounted for nearly 48% of all consents in the tertiary cancer centre. This model could be rolled out to truly put patients and the public at the centre of research activity.



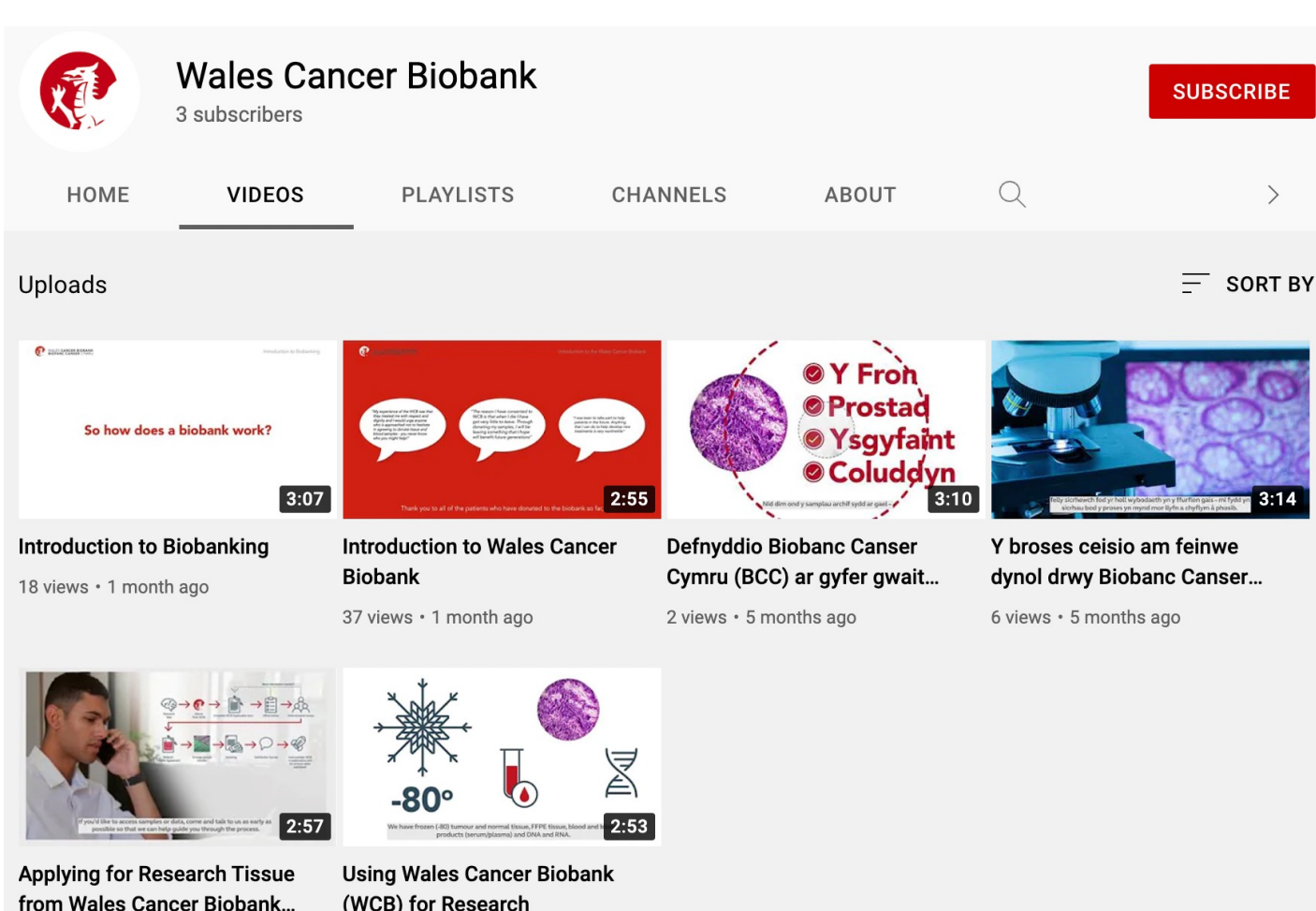
* Lay volunteer program is based on the program initiated by the Nottingham Health Sciences Biobank

Standards Mapping and Feedback



Feedback from the lay members has been hugely positive and all have reported feeling better informed, more involved and more valued. The members on the operational management group have commented that they had no idea the day-to-day operation was so complex and that the increased knowledge had changed the way they participate and the recommendations they contribute. A lay driven conversation has, for example, initiated the production of two videos aimed at the public to raise awareness and a major refresh of the website www.walescancerbank.com

Conclusions and Outputs



WCB now has its own YouTube channel to host the videos:
<https://www.youtube.com/channel/UCTzbTXmr--nsVmB8aOEzz6w>

and a new website



An informed lay voice has greater value to the biobank and gives greater purpose to the volunteer.

Embedding the lay representatives at the heart of all activity speaks to the vision of the biobank of improving impact and adding value by not only listening to lay representatives, but truly involving them in governance decisions that impact priorities and future agendas to improve outcomes.