SHARE Report for AGM 2020

SA Heart® Registry – SHARE Committee members

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The SHARE projects are bearing fruit, with some pleasing progress in existing registries in the time period before the Covid-19 lockdown. Plans for expansion to add 3 more registries in 2020 have been sidelined by the advent of Covid-19. The national shutdown has affected local medical practice and business in unexpected ways, from projects stalled due to regulatory and ethics approval bodies being closed or experiencing technological and resource challenges, to patients being unwilling to attend for visits at medical centres.

SHARE-TAVI registry is now running very well. We are excited to announce that the TAVI registry has reached the milestone of over 1000 implants captured since SHARE’s inception! Although we have now captured 1125 TAVIs, less than 130 TAVIs have been implanted in 2020 due to the dip in activity related to Covid-19. In comparison to the 231 TAVI that were captured across SA in 2018, and the 278 TAVIs captured in 2019, it is unlikely that implant numbers will reach 200 in total this year. Together with the cases captured, the registry tracks patients in the funding approval process, and 200 patients are awaiting decisions from the Funders. Although the approval process time has also been affected by the lockdown, some patients with approved TAVIs have declined the intervention for fear of contracting Covid-19 during their planned admission, and there has been mortality amongst these patients as a result. A further 200 patients are followed up to 1-year as they exited the TAVI programme after they were evaluated, the majority exiting due to declined funding or affordability issues where low value partial funding is offered by some Funders.

Several barriers still remain for access to this technology for appropriately selected patients. Geographically equitable access is being addressed with the establishment of new sites in less serviced provinces, however several Funders are resisting the establishment of additional TAVI centres. Data from the SHARE-TAVI registry presented in a poster at the SA Heart Congress 2019 showed that procedural success in the existing TAVI sites was both comparable with the favourable outcomes seen overseas in large registries and trials, and importantly in our low volume setting in SA, was independent of site volumes. This evidence from the locally obtained data from the SHARE-TAVI registry has been shared with Funders in an attempt to provide relevant information for their decisions in a South African setting, and it is hoped that by providing insight into the favourable outcomes seen in South Africa to date, that Funders will expand their support for the TAVI procedure. This type of liaison with Funders is considered an important part of the mission of the SHARE projects, which primarily aims to improve patient care, and facilitating access to appropriate care is regarded to be part of that mission. SHARE is also directing to publish the results from the registries, and has had several abstracts accepted at local and international meetings to this effect. This year abstracts were submitted and accepted by EuroPCR 2020 and the ESC Congress 2020. An ePoster with recorded audio presentation was displayed in the Best Moderated Poster channel at the ESC2020 – The Digital Experience, and received favourable responses.

The capture rate of 92% for database entries of TAVI in South Africa is very high and is impressive for a voluntarily subscribed registry. The SHARE office has used this time of low implant volumes to engage with practices regarding outstanding follow-up, and over 450 records have been edited and updated as a result. We have made use of a database linked to the Department of Home Affairs records, to verify dates of death for patients suspected of being deceased in cases of Lost to Follow-up. Outstanding follow-up remains a concern, but follow-up is being hampered by patients who do not want to attend their regular appointments for fear of Covid-19. This has delayed the planned analysis of the collated data for the manuscript.

As always, we remain grateful to our funders, and are happy to report that Medtronic and Edwards have continued to support the registry through various grants. We hope that as further industry members expand their product offerings to include TAVI implants, that they too will support the registry.

Prof Karen Sliwa of the Hatter Institute at UCT, and Dr Priya Soma-Pillay lead the SHARE Cardiac Disease and Maternity Registry (CDM), which has come to the end of its life cycle, data entry has been closed on this project and as Prof Sliwa’s responsibilities at WHF have increased, she has handed over the lead in reporting on this registry to Dr Ferial Aziubani, who is now in the process of preparing the first manuscript on this patient cohort.

The new Atrial Flutter/Fibrillation registry, SHARE-SAFFR, led by Dr Martin Mpe and Prof Ashley Chin, has been developed and tested by the Investigators, and ethics approval has been obtained for the initial sites. Further sites have been identified but the ethics approval process was disrupted and delayed during the lockdown period. Data capture has begun but only 25 patients were entered during the hard lockdown period due to difficulty getting patients to attend medical centres.

Having started this year on a positive note, and then having widespread disruptions due to the Covid-19 lockdown has been disheartening, but we look forward to a rally of progress and growth as 2020 ends and the New Year starts afresh. Despite the unexpected stumbling block of Covid-19 in 2020, we will continue to generate the type of local data and information that will influence and improve clinical practice, patient care, and public policy in the future. The committee remains thankful to individual members of SA Heart®, the SA Heart® Exco, Industry partners, Funders and hospital groups for their continued interest and support of SHARE, and of course most importantly to the participants at all our sites.

Elizabeth Schaafsma and Prof Mpiko Ntsekhe, Chairperson, SHARE Committee