



2 March 2021

ACFDR CONSUMER SURVEY

The Australian Cystic Fibrosis Registry (ACFDR) has been collecting data since 1998. It includes diagnostic and treatment data for over 90% of the Cystic Fibrosis (CF) population in Australia, leading to a greater understanding of the disease's characteristics and the standard and type of care provided.

The ACFDR is housed at Monash University. The Monash Registry Database security is maintained using encryption of data. Encryption is the process of translating data into a secret format so that only authorised parties can understand the information. Access to information collected by the ACFDR is subject to strict protocols and procedures to ensure that privacy, confidentiality and ethical principles are maintained at all times. Only anonymous data (that cannot identify individuals) is shared outside of the Australian CF Registry.

The registry currently does not capture participants' names, surnames nor addresses. This becomes very difficult for the Registry team to conduct research and perform data linkages with other datasets, such as hospitalisation, admission, transplant datasets and others. The newly linked data may contain duplicate entries and erroneously linked records belonging to different individuals. Such problems can be overcome through the use of identifiable data.

The ACFDR would like to align with the international CF Registries such as those from the USA, UK, and Europe to collect identified personal data. Proposed personal data to be incorporated into the Registry includes the full surname, full given name, residential address, email address and telephone number. This will lead to improved data quality by reducing data errors in the Registry, enhance data linkage, analyses and consumer access to quality data.

Please give us your thoughts [HERE](#) by completing a very short 2 minute survey.

SURVEY CLOSING FRIDAY 5TH MARCH.

Kind regards

A handwritten signature in black ink that reads "Nettie Burke". The signature is written in a cursive, flowing style.

Nettie Burke, CEO
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