Using DSpace to create a repository for the communication of clinical trials and research with consumers

Hannah-Lee Obst
South West Healthcare
hobst@swh.net.au | https://orcid.org/0000-0002-7858-4099

Background

Consumer involvement in research and clinical trials is expected as part of Standard 2 of the National Clinical Trials Governance Framework (Australian Commission on Safety and Quality in Health Care, 2022).

Consumer involvement in research improves public awareness of, and support for, science and research, and ensures that research is relevant to community needs (NHMRC, 2016). Consumers defined here as patients and potential patients, carers, and people who use health care services, should be engaged in all facets of the research process (Australian Clinical Trials Alliance, 2023). However, consumer involvement in dissemination and even gaining access to study results is less likely to occur than consumers being involved in the initial design and recruitment stages (McKenzie, 2022).

Historically it has been a difficult task for consumers and members of the public to find research output from South West Healthcare (SWH). It can be time consuming without training or access to research databases.

Even internally, there was a lack of communication of research outcomes across the organisation. Research is conducted, completed, but not disseminated to the organisation. The library attempted to stay abreast of publications and share these via our monthly newsletter. Not all studies conducted at our organisation closed the research loop with the ethics and governance office, reported published outcomes, or shared research findings with the consumers who participated in the studies. A further issue is that many of our staff members choose to affiliate primarily, and sometimes solely, with their university affiliation. The university is often the party who has paid for the paper to be published. This again makes it hard to link research that is occurring in our health service with us.
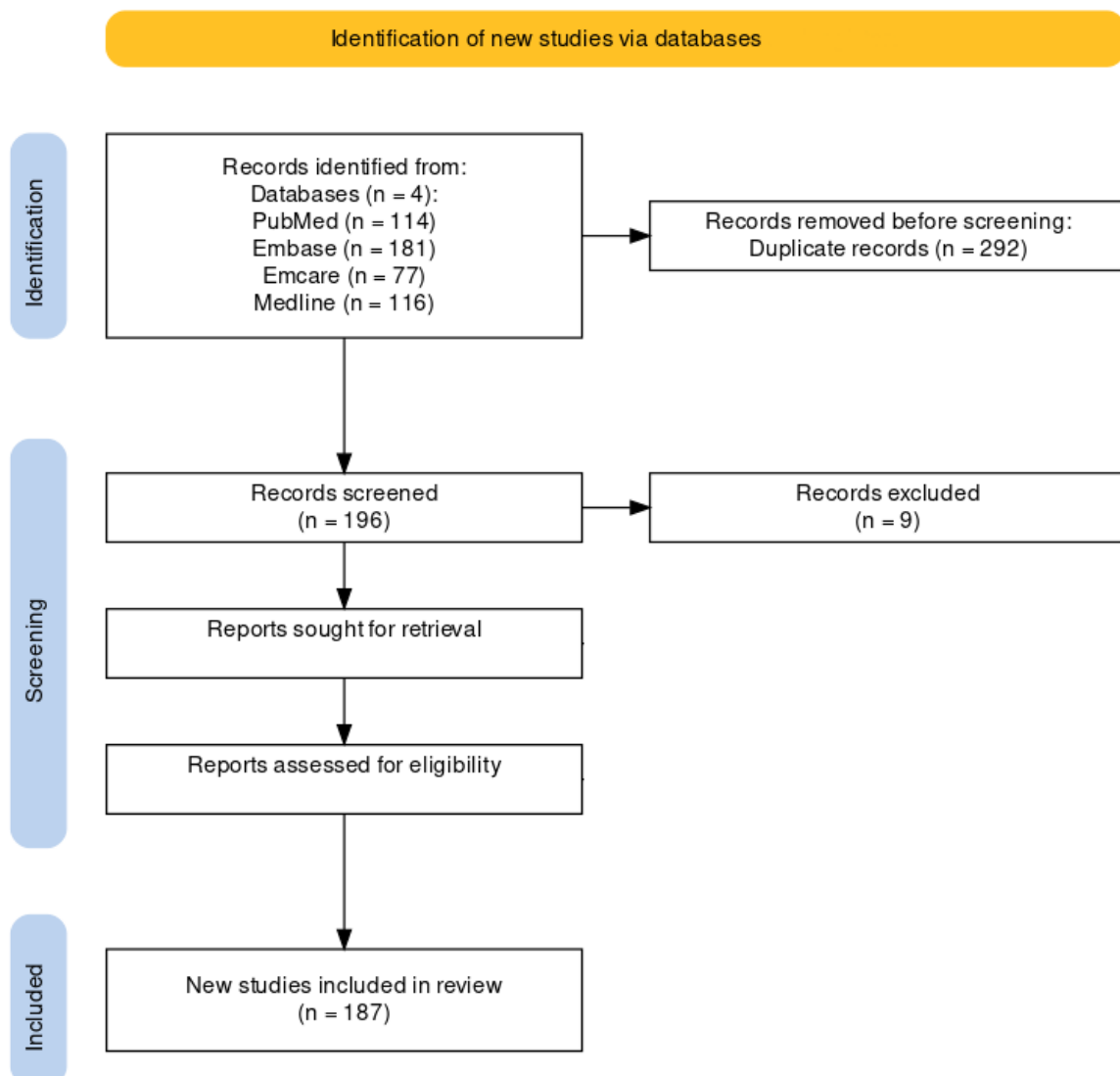
To address this issue, the Library, with support from the Research Office, created a digital repository using the DSpace platform. A digital repository provides staff with an effective means of disseminating their research findings, including open access publications. DSpace is an open-source digital repository that provides users with the ability to capture, store, and share a wide variety of digital content.

Search Methodology

The initial gathering of content for the repository was conducted across the following databases: PubMed, Embase (Ovid), Emcare (Ovid), and Medline (Ovid).

The following search teams that had been identified as author or contributor affiliations were used: "South West Healthcare"; "South West Health Care"; "Southwest Healthcare"; "South West Regional Healthcare"; "South West Regional Hospital"; "Camperdown Base Hospital"; "Camperdown Hospital"; "Warrnambool Base Hospital"; "Warrnambool Hospital".

The resulting articles were screened to identify if one of the authors was a SWH staff member or if the research was conducted using SWH data. Searches were exported into EndNote and duplicates were removed. Excluded studies included authors affiliated with South West Healthcare Services and South West Healthcare Systems which are two unrelated American organisations. Article alerts based on this have now been set up on these databases to help us identify studies as they are published.

Secondly, the library searched for the names of known South West Healthcare authors on these databases as well as Google Scholar, ResearchGate and ORCID pages.

Finally, we reached out to staff via the library newsletter to share their publications.

Repository Development Methods

SWH engaged Prosentient Systems to help with initial site configuration and hosting of the DSpace. The site was branded to match with the SWH website and given the subdomain repository.southwesthealthcare.com.au

Prosentient Systems staff along with SWH research and library staff spent time developing the site configuration and required metadata field requirements for item submission.

The first batch of articles were bulk imported from the resulting EndNote library from our affiliated authors search. Additional metadata indicating SWH author and department was added. Initially two collections were created, SWH Staff Publications and SWH Data Contributions, which together make up the SWH Research Repository. A secondary collection, the Historical Archive, has since been developed. This collection contains annual reports and historical images from our health service. From the repository landing page users can search by collection or discover content by author, subject or content type.

Project benefits – for South West Healthcare

Easy Access to Digital Content - the digital repository provides users with easy and reliable access to their digital content. With a user-friendly interface researchers, librarians, and other staff can easily find and access the information they need.

This repository is still developing, being less than 6 months old, and we continue to look at ways to enhance access, better embed content and provide article requesting for behind paywall articles.

Improved Research Efficiency - the digital repository provides a centralised location for storing and managing research data, making it easier for researchers to collaborate, share, and build upon existing research.

As we prepare for our first National Clinical Trials Governance Framework accreditation we are working closely with our Clinical Trials and Quality teams. The repository is one of our strategies to meet some of the actions in the framework.

Capturing Research Output - the digital repository enables SWH to encapsulate and assist in disseminating research outputs generated or contributed to by our staff. This enhances the potential for inclusive, accurate reporting and the potential for translation of research outputs into service improvements.

The repository has increased visibility of research outputs, and extended the reach of our content. Items that may have previously only been findable internally can now be cited from Google Scholar. We launched the Digital Repository at our first ever Research Celebration day in May 2023. Poster presentations from that day were able to be loaded to the Digital Repository and were indexed and findable in a Google Scholar search almost immediately.

Project benefits – for the wider community

Increase community awareness and engagement – the repository highlights the diverse activities that take place within the organisation. By consolidating and organising digital content, the SWH repository makes it easier to locate, access, and share research beyond the organisation. There is still marketing activities to be done, but our health service communications team are starting to make use of the items we load.

Closing the research loop - Consumers become engaged in the research they are participating in. The SWH Digital Repository is linked directly from the SWH website research pages. The goal is for researchers and the research office to be able to share direct links to content for anyone wishing to know the outcomes of a study they may

have participated in. In the future we want to work with the Clinical Trials team to tag research articles to trial names and registration number so users can sort by trial.

Preservation of Historical Records - The digital repository can be used to preserve our archival history. We can ensure that historical records are safe, secure, and easily accessible to staff and the public. The library was often asked to provide images to the media team or members of the public related to our staffing, nurse training or hospital history. As we catalogue more images to this repository it makes it easier for users to find relevant content.

References

Australian Commission on Safety and Quality in Health Care. (2022). The National Clinical Trials Governance Framework and user guide for health service organisations conducting clinical trials. Retrieved from https://www.safetyandquality.gov.au/publications-and-resources/resource-library/national-clinical-trials-governance-framework-and-user-guide

Australian Clinical Trials Alliance. (2023). Consumers. Retrieved from https://involvementtoolkit.clinicaltrialsalliance.org.au/consumers

Haddaway, N. R., Page, M. J., Pritchard, C. C., & McGuinness, L. A. (2022). PRISMA2020: An R package and Shiny app for producing PRISMA 2020-compliant flow diagrams, with interactivity for optimised digital transparency and Open Synthesis. Campbell Systematic Reviews, 18(2), e1230. https://doi.org/10.1002/cl2.1230

McKenzie, A., Bowden, J., Zalcberg, J.R. et al. (2022). A snapshot of consumer engagement in clinical trials in Australia: results of a national survey of clinical trial networks and research organisations. Research Involvement and Engagement, 8(3). https://doi.org/10.1186/s40900-022-00338-w

NHMRC. (2016). Statement on Consumer and Community involvement in Health and Medical Research. National Health and Medical Research Council, Consumers Health Forum of Australia