## **CASE STUDY**

## **Engaging teenagers and their guardians in long term research**

The Longitudinal Study of Teenagers with Endometriosis, Period and Pelvic Pain (LongSTEPPP) is a 5-year Australian observational study lead by the Murdoch Children's Research Institute. The study uses surveys completed by teenage participants (10 – 18 years old) and their guardians and combines this data with information collected by other health services to investigate optimal care for young people with period and/or pelvic pain.

When designing the longitudinal study, the researchers ran a focus group with teenage participants from a previous study. This focus group specifically asked about communication preferences, including the types of information they would like to receive and what channel would be best to distribute that information. The group identified that they would like informational video content, preferably via social media such as Instagram, TikTok and Snapchat. There was also a preference for text messages over phone calls, emails or printed materials.

This feedback was incorporated in the design of a short (3 minute) study information video to help teenage participants through the consenting process. The study team have also been developing a series of “period myth busting” videos which are freely available online.

During the study, both teenage and guardian participants receive annual surveys via email – administered through REDCap – and quarterly study updates in the form of a newsletter. Study updates are also delivered via the project’s Instagram channel @longstepppstudy, which all participants are invited to join. The updates include information about study progress, stories or art shared by the participants, and may include information about relevant advocacy events or opportunities (e.g. R U Ok day, National Pain Week, and the Victorian Inquiry into Women’s Pain).

At the end of the study participants will receive a letter with the study results, which will include an infographic, codesigned with teenage consumers. This will be shared with participants via the Instagram channel as well as more broadly to GPs and Gynecologists who have subscribed to receive study updates.

Because this project primarily targets teenagers who are considered a hard-to-reach population, the study team put a lot of effort into codesigning study measures and communications. This has been well received by participants with over 270 teenagers recruited to date.

The study team notes that the use of social media and video content was essential to successful communication with the teenage participants, but seeking approvals for this was time consuming. They would encourage others to employ the principles of co-design and endeavor to use the preferred communication channels of the participants.