# Cystic Fibrosis Research News

**Title:** Electronic Monitoring Reveals Highly Variable Adherence Patterns In Patients Prescribed Ivacaftor

**Authors:**
Christopher M. Siracusa, MD[a]
Jamie Ryan, PhD[b]
Lisa Burns, MD[a]
Yu Wang, MS[c]
Nanhua Zhang, PhD[c]
John P. Clancy, MD[a]
Dennis Drotar, PhD[b]

**Affiliations:**

a. Division of Pulmonary Medicine, Cincinnati Children's Hospital Medical Center (CCHMC). 3333 Burnet Ave, Cincinnati, OH 45202
b. Division of Behavioral Medicine and Clinical Psychology, CCHMC. 3333 Burnet Ave, Cincinnati, OH 45202
c. Division of Biostatistics and Epidemiology. CCHMC. 3333 Burnet Ave, Cincinnati, OH 45202

**What was your research question?**

We aimed to observe and measure patterns of adherence to ivacaftor over time by using multiple measures of adherence.

**Why is this important?**

Until recently, treatments for cystic fibrosis (CF) were focused on minimizing symptoms and slowing disease progression. The traditional treatment for people with CF often includes a time-consuming and sometimes burdensome routine. Past studies have shown that adherence to CF treatments varies, and is usually less than optimal. In 2012, ivacaftor (also known as Kalydeco™) became the first approved medication of its type, to treat the underlying cause of CF – a defective protein on the surface of the cells that line the lungs, pancreas, digestive tract, sinuses, and other organs of the body. Despite the promising

nature of this new medication, there was concern that patterns of adherence to this medication would be similar to other CF treatments.

**What did you do?**

In our study we observed participants for about 4 months and looked at their adherence to ivacaftor. While there are multiple ways to measure adherence, we attempted to get the most accurate information by using electronic pill bottles that recorded every time the bottle was opened. We then compared this information to how often the participants reported missing a dose, as well as the pharmacy refill history.

**What did you find?**

In general, adherence rates show the number of times a patient takes a medication as prescribed. According to the electronic monitors, in this study adherence rates were 61% on average, though they were highly variable. Also, the time between doses (which should be 12 hours), averaged 17 hours. We also found that both the overall adherence rates, and time between doses, worsened over time.

Finally, when we compared electronic monitoring to other ways of measuring adherence, they did not match up. The average adherence rate as reported by the participants was 100%. The average adherence rates shown the by pharmacy refill history were 84%, and were also highly variable.

**What does this mean and reasons for caution?**

Overall, our findings suggest that, despite the promising nature of this class of medications, adherence rates are poor and similar to rates of other CF treatments. We also found that there was significant variation among measures, and a more accurate tool is needed to help clinicians assess adherence.

We know that there are lots of reasons why patients have issues with adherence to treatment. Many of these barriers can be addressed at a systems-level (e.g. insurance coverage), though often the barriers can reflect a person's thoughts and behaviors (e.g.

forgetting to take medications, being too busy to complete therapies, feeling the treatments do not make a difference).

**What's next?**

Ultimately, patients and their families have a great opportunity to improve both their adherence and the positive impact of ivacaftor therapy by working with their treatment team to identify the barriers that decrease their adherence and to develop effective ways of removing them. Future studies will focus on these barriers, and how we can minimize them and/or help patients and families cope with them.

**Original manuscript citation in Pubmed**

**http://www.sciencedirect.com/science/article/pii/S1569199315001241**