

Patient Activation: Possessing the knowledge, skills and confidence to actively engage in your health and change behaviours where needed to achieve better health outcomes.

The Patient Activation Measure (PAM) questionnaire tool has been well validated and studied in adult populations but there is limited data on its use in the paediatric population.

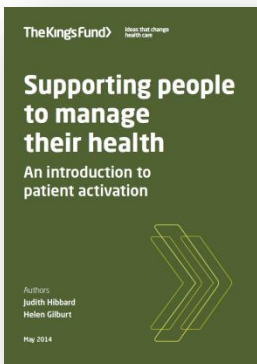
The Parent PAM was administered in paediatric Cystic Fibrosis clinics. 87 Caregivers completed the questionnaire.

Level 1—does not believe the caregiver role is important (score ≤ 47.0)

Level 2—does not have the confidence or skill to take action (≥ 47.1 and ≤ 56.9)

Level 3—may begin to take action (≥ 57 and ≤ 70.9)

Level 4—takes action, may have difficulty maintaining behaviours over time (≥ 71)



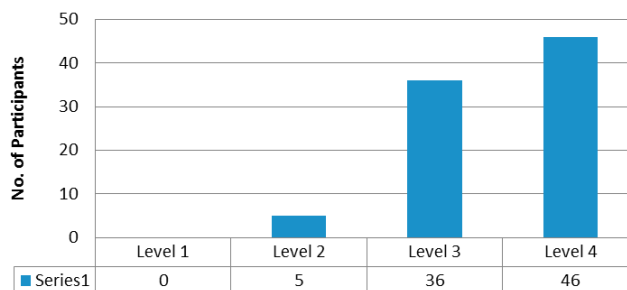
Parent Patient Activation Measure[®]

Below are 10 statements that people sometimes make when they talk about their child's health. Please indicate how much you agree or disagree with each statement as it applies to you and your child by circling your answer. If the statement does not apply to you, circle N/A.

Statement	Disagree	Disagree	Agree	Agree	N/A
1. I am the person who is responsible for taking care of my child's health.	Disagree	Disagree	Agree	Agree	N/A
2. Taking an active role in my child's health is a waste of time.	Disagree	Disagree	Agree	Agree	N/A
3. I am confident that I can take action to help prevent major problems associated with my child's health.	Disagree	Disagree	Agree	Agree	N/A
4. I know what each of my child's medical conditions are.	Disagree	Disagree	Agree	Agree	N/A
5. I am confident that I can get what I need to help my child's health problem solved.	Disagree	Disagree	Agree	Agree	N/A
6. I am confident I can talk to a doctor or nurse the way that I need to get my child's health problem solved.	Disagree	Disagree	Agree	Agree	N/A
7. I am confident that I can carry out medical treatments I need to do for my child at home.	Disagree	Disagree	Agree	Agree	N/A
8. I understand the advice health professionals give about my child's health problem.	Disagree	Disagree	Agree	Agree	N/A
9. I am confident that I can take action to help my child's health problem.	Disagree	Disagree	Agree	Agree	N/A
10. I have been able to help my child manage their condition with changes to their health care routine.	Disagree	Disagree	Agree	Agree	N/A
11. I keep track of my child's health problem.	Disagree	Disagree	Agree	Agree	N/A
12. I am confident I can work out solutions when new problems arise with my child's health.	Disagree	Disagree	Agree	Agree	N/A
13. I am confident that I can help my child understand their condition, the health care they need to manage it, and what to do if things change.	Disagree	Disagree	Agree	Agree	N/A

The average PAM score is 73.8 (level 4)

A Count of Scores Achieved in PAM for Cystic Fibrosis



Parents of children with CF in a regional cystic fibrosis centre show high levels of patient activation. This tool, though not specific to CF, when administered to parents can give insight into the level of healthcare engagement of this population.