

Co-designing a model of care for adults living with Cystic Fibrosis Related Diabetes

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Abstract

Background Cystic fibrosis (CF) related diabetes affects up to half of all adults with CF and is associated with higher morbidity and mortality. Our aim is to co-design an ideal model of care that integrates diabetes technology and better meets the needs of adults living with the condition to improve attendance, engagement, service satisfaction and clinical outcomes. **Methods** Using qualitative research methods, we evaluated disease perceptions, barriers and enablers to optimal CF-related diabetes management and service delivery. Integration of continuous glucose monitoring (CGM) was also explored. An initial broad purposive consumer survey was followed by focus groups with end-users. Grounded theory approach was utilized with major problem-areas identified then explored, coded and grouped into requisites for an ‘ideal model of care’ for adults living with CF-related diabetes. **Results** Two key themes emerged i) CGM was acceptable for use in adults with CF-related diabetes with many perceived benefits and should be integrated into the model of care, ii) an ideal model of care consisted of a dual-specialty service co-led by endocrinology and CF physicians and supported by diabetes nurse educator and CF dietitian with a goal to provide consistent and personalized diabetes management. Barriers to optimizing glycaemic control included diet, finger-prick testing, reduced access to CGM and pulmonary exacerbations. End-user feedback on CGM was overwhelmingly positive with regards to user operability. CGM was also identified as a tool that could be used to engage, educate and empower adults living with CF-related diabetes and facilitate constructive and personalized clinical decision-making by healthcare providers. **Conclusion** For adults living with CF, a diagnosis of diabetes is associated with increased treatment burden. End-users agreed CGM had many benefits and should be integrated into an ‘ideal model of care’ for CF-related diabetes that was co-led by endocrinology services integrated within a pre-existing CF service.

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