

# Breaking Down Barriers

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Ehlers-Danlos Support UK (EDS UK)

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The Sylvia Adams Charitable Trust



**Alström Syndrome UK**  
Strength for today, hope for the future

# Project Overview

## Year 1

- Raised awareness in South East Asian communities in East London of the Ehlers-Danlos syndromes (EDS) and the support available from EDS UK. Tried to engage 'difficult to reach' communities.
- Distributed translated materials via 40 places of worship, held event at East London mosque, promoted project on Big Debate Show, BBC Asian Network.

## Year 2

- Continue to raise awareness of EDS and offer support but this time via GP surgeries in Tower Hamlets, London (high BAME population)
- Working with QMUL Centre for Primary Care and Public Health to identify suitable GP practices, we will use our new EDS toolkit for GPs to identify people from the practices' databases who may have EDS but have not been diagnosed. [Toolkit: [www.rcgp.org.uk/eds](http://www.rcgp.org.uk/eds) includes what EDS is, how to diagnose and how to treat]
- Our Primary Care Advisor (a GP) will try to engage with the 4-6 GP practices using the EDS toolkit and examples from her own practice. She will identify patients with a high frequency of visits, following a pattern which could indicate EDS. She will suggest an EDS management plan (will be patient-specific and based on GP toolkit) and ask GPs to provide translated materials about EDS and the charity (from yr 1) for the identified patients (if EDS is confirmed)
- Impact measurements still to be determined but likely to be based on GP feedback on number of patients identified and 'successfully' treated



# Challenges

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- Year 1 approach has not yet delivered the impact we had hoped for (i.e. contact with the charity from SE Asian communities has not significantly increased)
- Financial challenges led us to restructure slightly after year 1. This meant the project team had to change. We decided to propose a project that involved two external partners instead (a GP and a Primary Care and Public Health expert from Queen Mary University, London) and it was difficult to get the approach agreed. This is still ongoing
- We expect the involvement of external partners in year 2 will make the project more challenging to manage
- We are dependent on GP practices being willing to participate in the project

# Areas of Success

- **Raising awareness of EDS and the charity**
  - Positive and fulfilling engagement with communities through visiting places of worship to distribute information
  - Successful event at East London mosque in Nov 2017 with approx. 6,000 attendees
- **Raising awareness of Breaking Down Barriers project**
  - Securing slot of The Big Debate Show on BBC Asian Network
- **Attracting more diverse supporters to the charity** (although difficult to directly attribute to the project)
  - Ambassador - Anoushé Husain (pictured); award-winning disabled climber with EDS. Helps to promote accessible exercise to benefit the conditions and promotes the charity's work in general
  - The Sandhu Charitable Foundation



# Questions



# Thank You



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