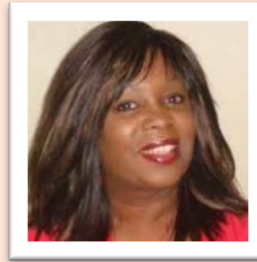


Storytelling is not just for bed time



Presenter



Sondra Butterworth

Community Psychology Specialist

Ataxia & Me Volunteer



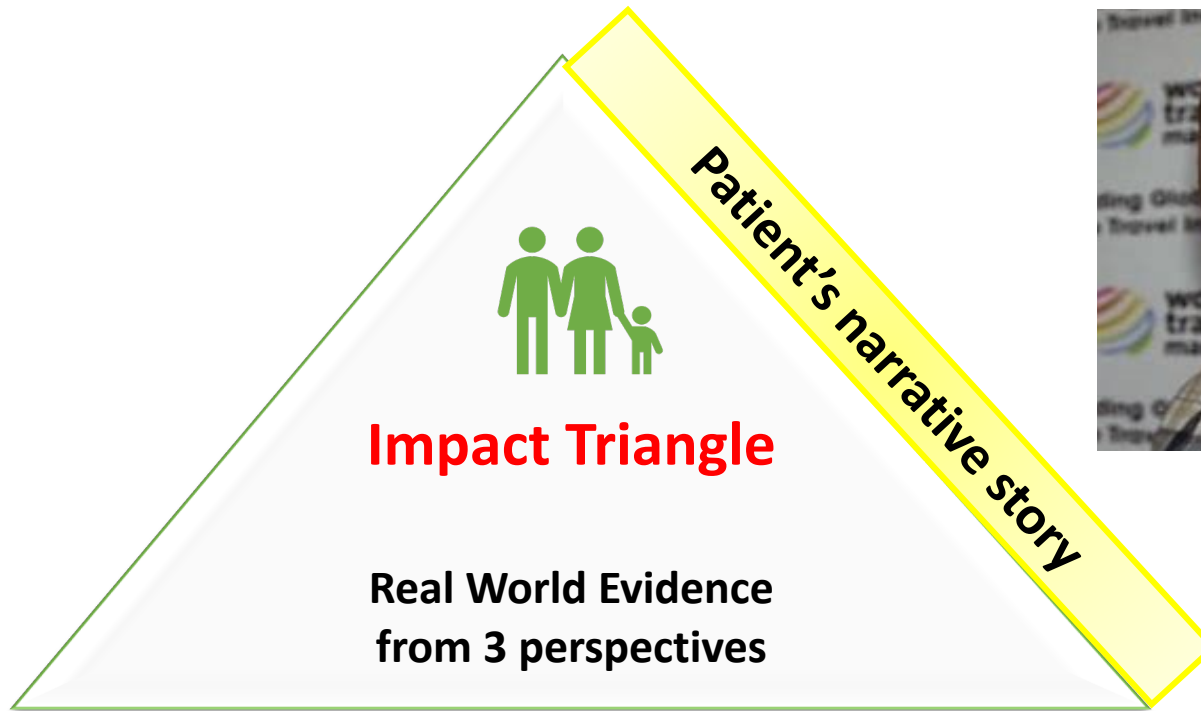
Storytelling is not just for bed time



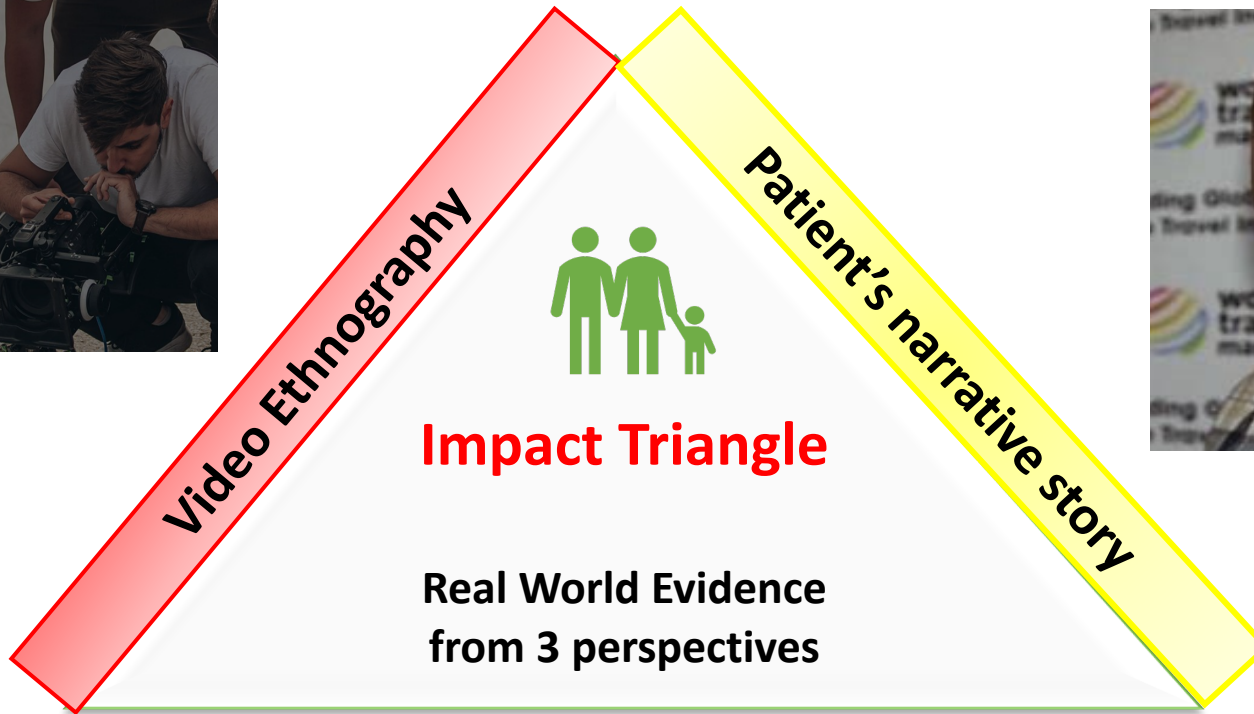
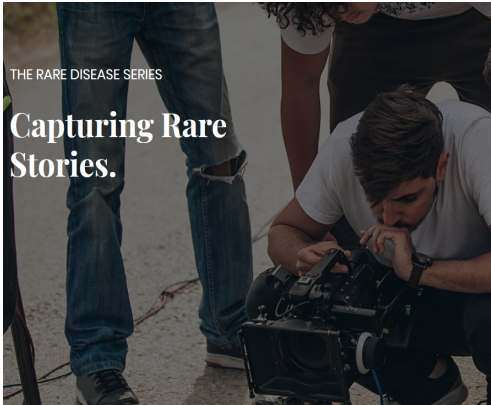
Impact Triangle

Real World Evidence
from 3 perspectives

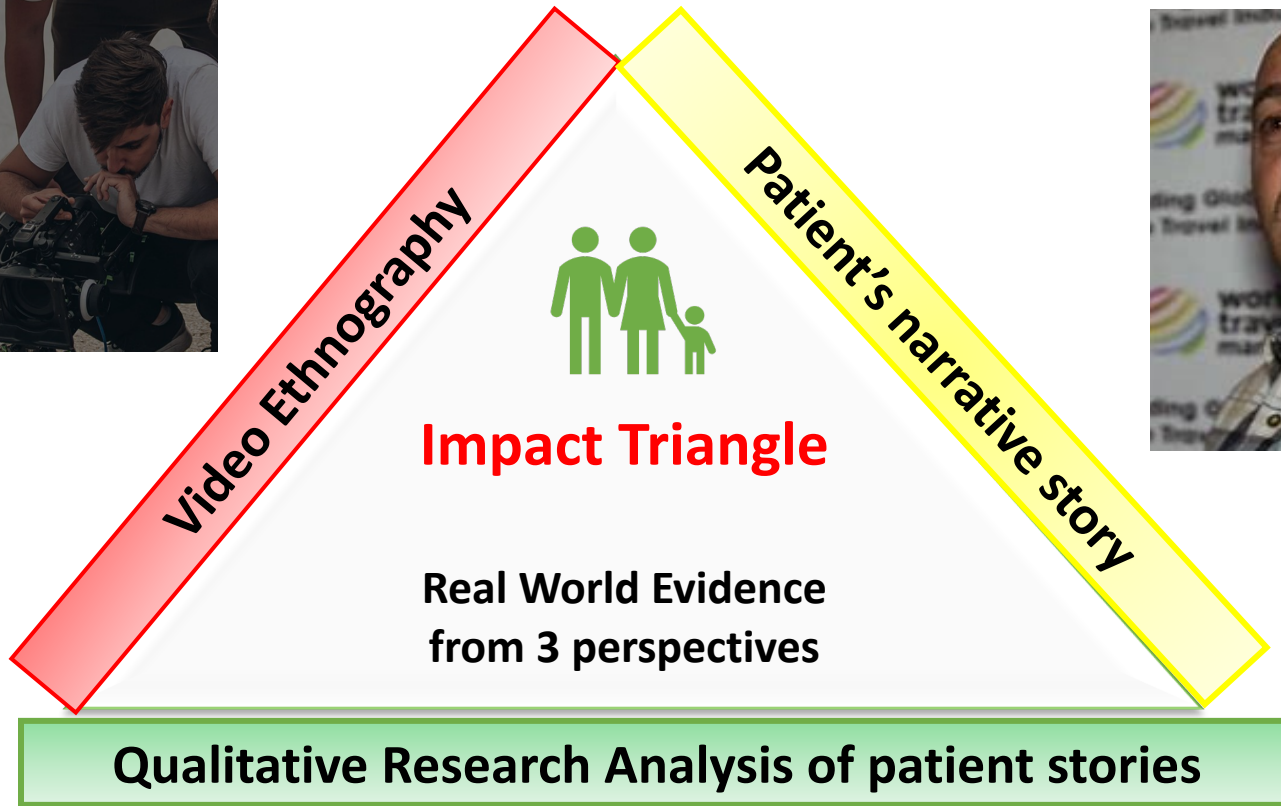
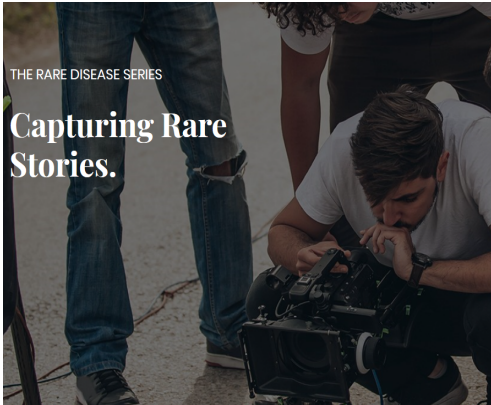
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One of the key end points of any PhD study is to provide robust results and demonstrate the impact of the research.

To this end we are planning to facilitate a Quality of Life story telling event in Cardiff.

The aim of this event will be to present some of the learning from the Quality of Life and social Support research study.

We want promote the use of the storytelling in research through the concept of the collaborative approach of The Impact Triangle.

PhD Study

The aim of this study was to explore the relationship between Quality of Life and Social Support. Those participants who were involved in the research were adults with diagnosed rare genetic skin and connective tissues conditions including Ehlers-Danlos Syndrome (EDS) and Epidermolysis Bullosa (EB).

Outcome

Negative experiences:

Some participants reported that they felt a sense of isolation, stigma, and lack of understanding about their condition and psycho-social needs.

Positive and inspirational findings:

Some participants reported feelings of taking control their lives, having a sense of hope and a need to support their own Rare Disease Community.



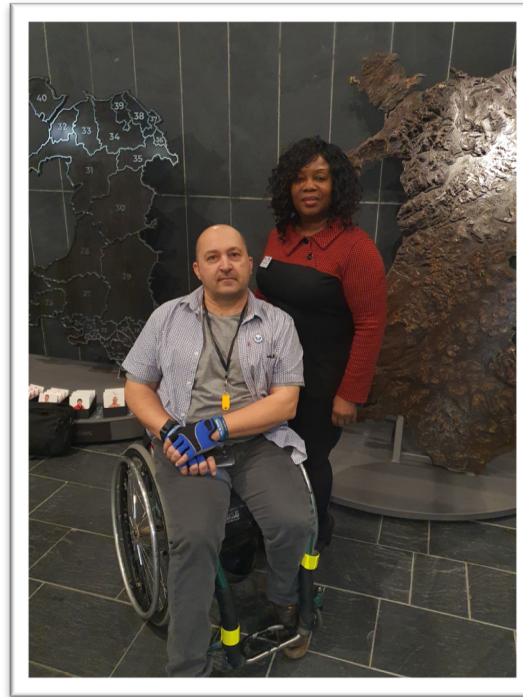
Storytelling is not just for bed time



Alan Thomas

Ataxia & Me Founder

Ataxia expert through experience



Sondra Butterworth

Ataxia & Me Volunteer

Rare Storyteller

Community Psychology Specialist

.....the next step.. a Quality of Life Storytelling event in Wales.

NB: Currently looking for sponsors

Presenting at the MediWales Member's Showcase 3rd March 2020