

Creative and person-centred approaches for studying health experiences of vulnerable individuals across the lifespan

Chair: Dr Lesley Baillie

Speakers:

Professor Jane Coad,

Dr Rachel Taylor,

Dr Michelle Evans

Debbie Chagadama

Dr Tiritega Mawaka



Symposium aim

- To showcase a series of five studies representing research undertaken in populations generally described as ‘vulnerable’ or challenging.
- The presentations focus on:
 - the challenges faced researching these patient groups
 - the diverse, innovative methods used to overcome the challenges.

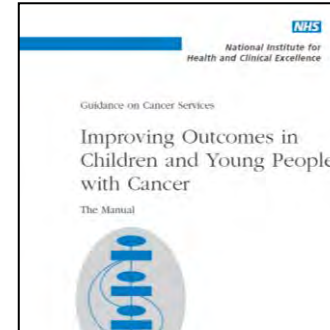


The challenge of measuring teenage and young adult experience of cancer in a longitudinal study

Rachel Taylor on behalf of the
BRIGHTLIGHT team



Reason for the research



Do specialist cancer services for teenagers and young adults add value?





Four points remain unclear

1. What is specialist care?
2. What are the core parts of this service?
3. How much does this cost?
4. What outcomes are associated with specialist care?



BRIGHTLIGHT

- BRIGHTLIGHT is an NIHR PGfAR
- Overall aim is to evaluate TYA cancer services through a series of inter-connected studies
- Central to BRIGHTLIGHT is a Cohort Study
- Aims: What outcomes are associated with specialist care?
 - Impact of specialist care on outcomes, experience and processes of care
 - Socio-demographic and geographic inequalities in access to specialist care

Young person involvement

The Essence Echo

Informing teenagers and young adults with cancer since 2009

Essence of Care study: Phase 1 complete

Researchers, including a team of young people with cancer, who have been working towards making young people's lives better when they have cancer, are pleased to announce the results.



Read on if you would like to know more...





BRIGHTLIGHT participants

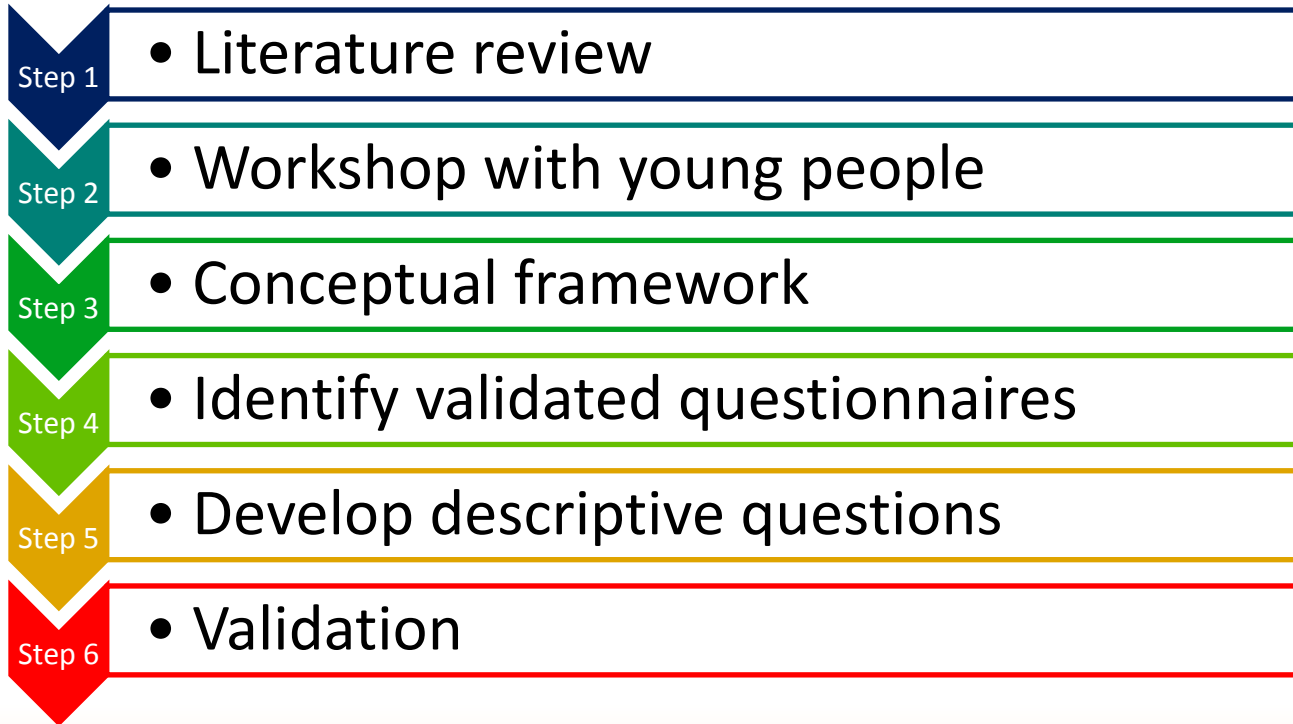
- The BRIGHTLIGHT includes 1,114 young people
- Inclusion criteria:
 - Diagnosed between July 2012 and December 2014
 - Aged 13 – 24 at the time of diagnosis
 - Resident in England at the time of diagnosis
 - Recruited within 4 months of diagnosis
- Exclusion criteria
 - Not capable of completing the survey
 - Recurrence of previous cancer
 - Death is imminent
 - Receiving a custodial sentence at time of treatment



Data collection

- Capturing experience = qualitative methods
 - Prohibitively expensive
- BRIGHTLIGHT Survey
 - Longitudinal study over 3-years therefore essential the survey reflects what is important to young people

BRIGHTLIGHT Survey





Step 1: literature review

- Systematic search of *published* qualitative studies on TYA cancer experience
- Meta-synthesis of 17 publications (15 studies)
- Nine common themes
- Conceptual model of TYA cancer care

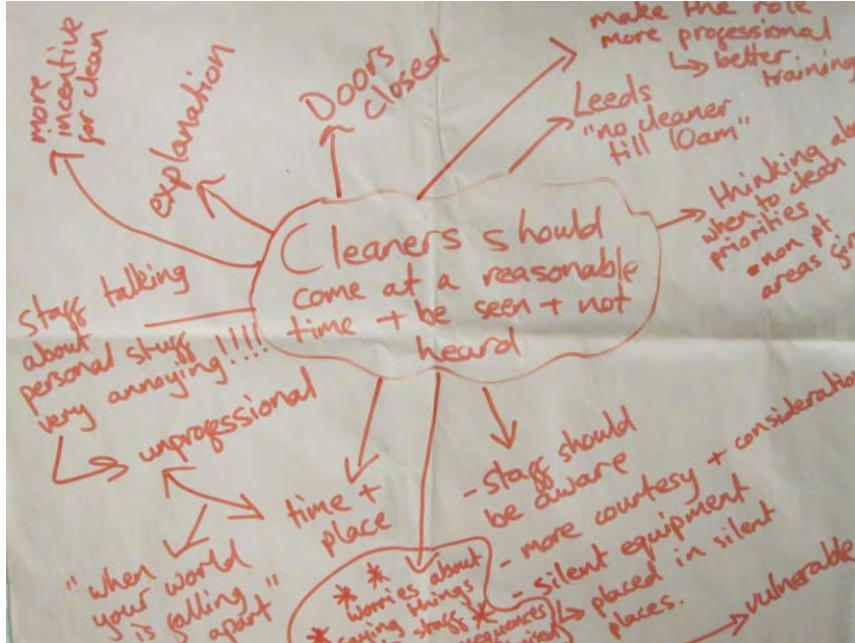
(Taylor et al. 2013 IJNS)



But...

- Long-term emotional consequences
- Aspects of place of care young people value most
- Expectations of different services and professionals
- Impact on school – what about higher education/careers/relationships
- Symptom experiences

Step 2: workshop with young people



The Essence Echo

Informing teenagers and young adults with cancer since 2009

Essence of Care study:

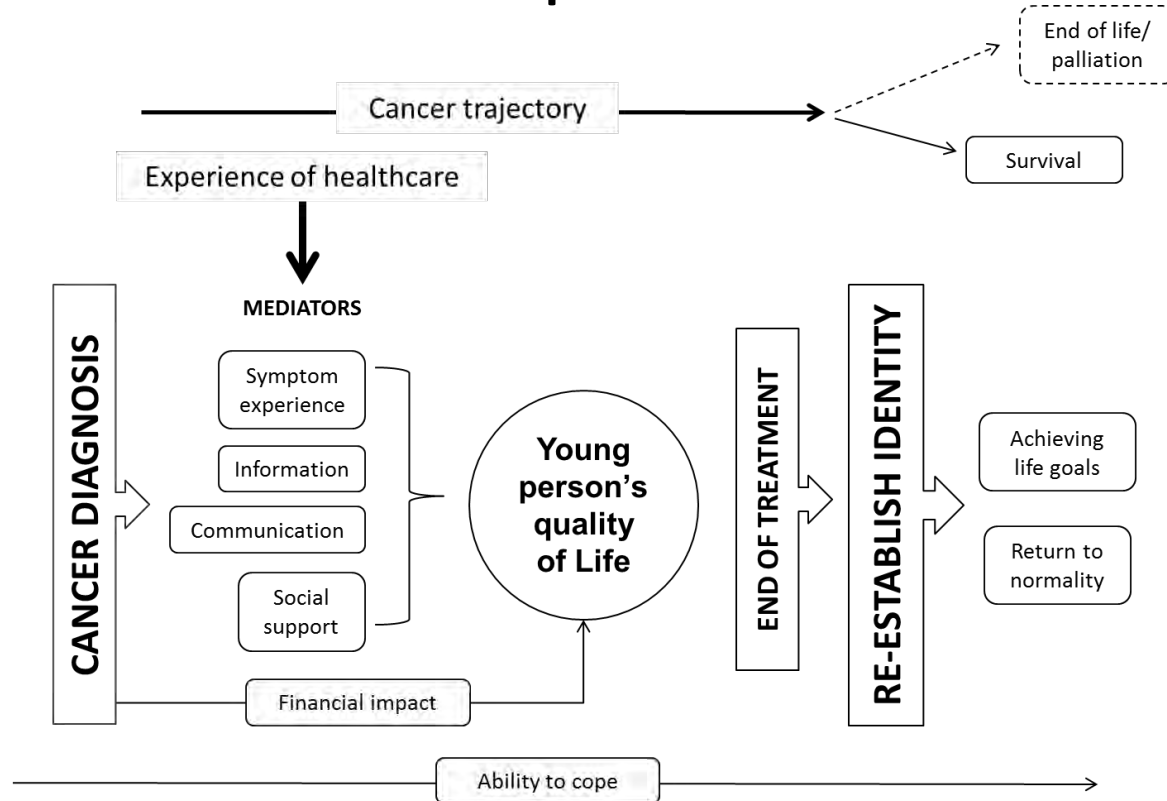
Phase 1 complete

Researchers, including a team of young people with cancer, who have been working towards making young people's lives better when they have cancer, are pleased to announce the results.



Read on if you would like to know more...

Conceptual framework

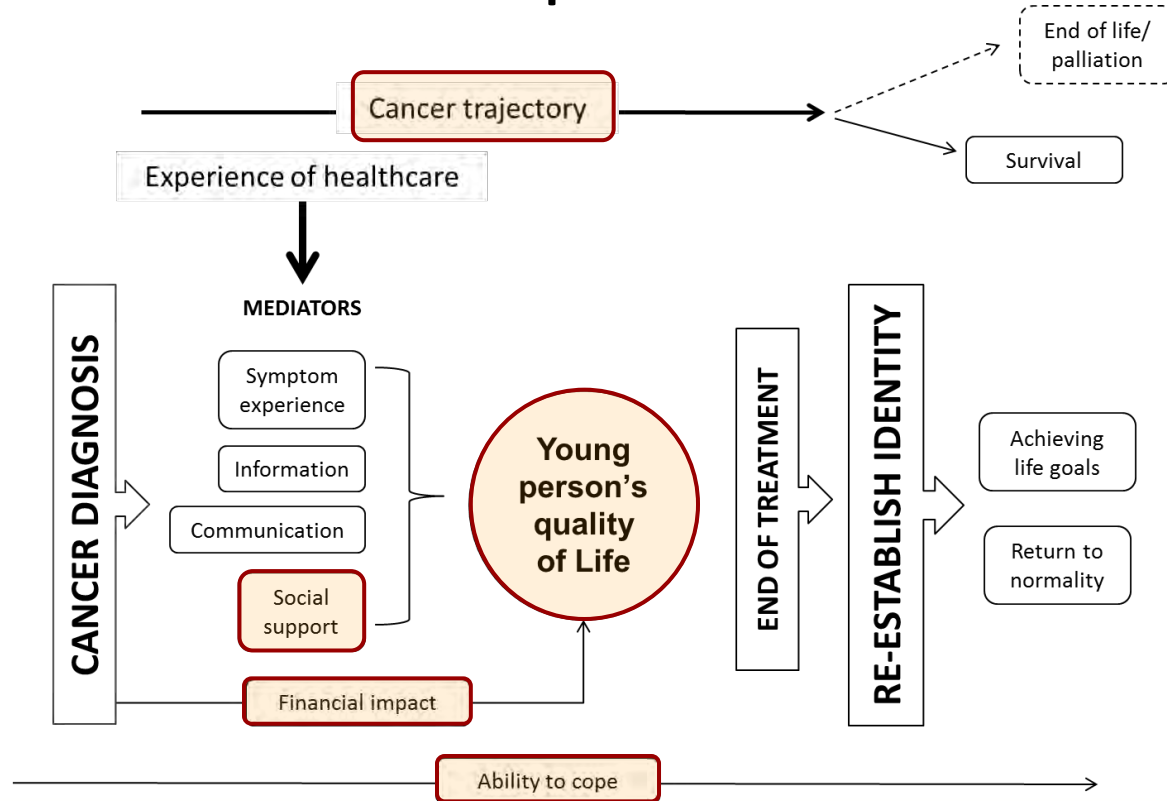




Step 3: Identifying questions

- Literature searches
- Young people's experiences (Taylor et al. 2013 IJNS)
 - Other non-published & ongoing studies
- Quantitative literature
 - What questionnaires have been used with TYA?
 - What questionnaires are validated for TYA?

Conceptual framework





Patient-experience questions



Symptom to diagnosis
Diagnosis
Place of care
Health professionals
Communication
Treatment
Clinical trials
Acute toxicity



Education
Employment
Relationships



Adherence
Fatigue
Fear of recurrence



Step 4: Validation

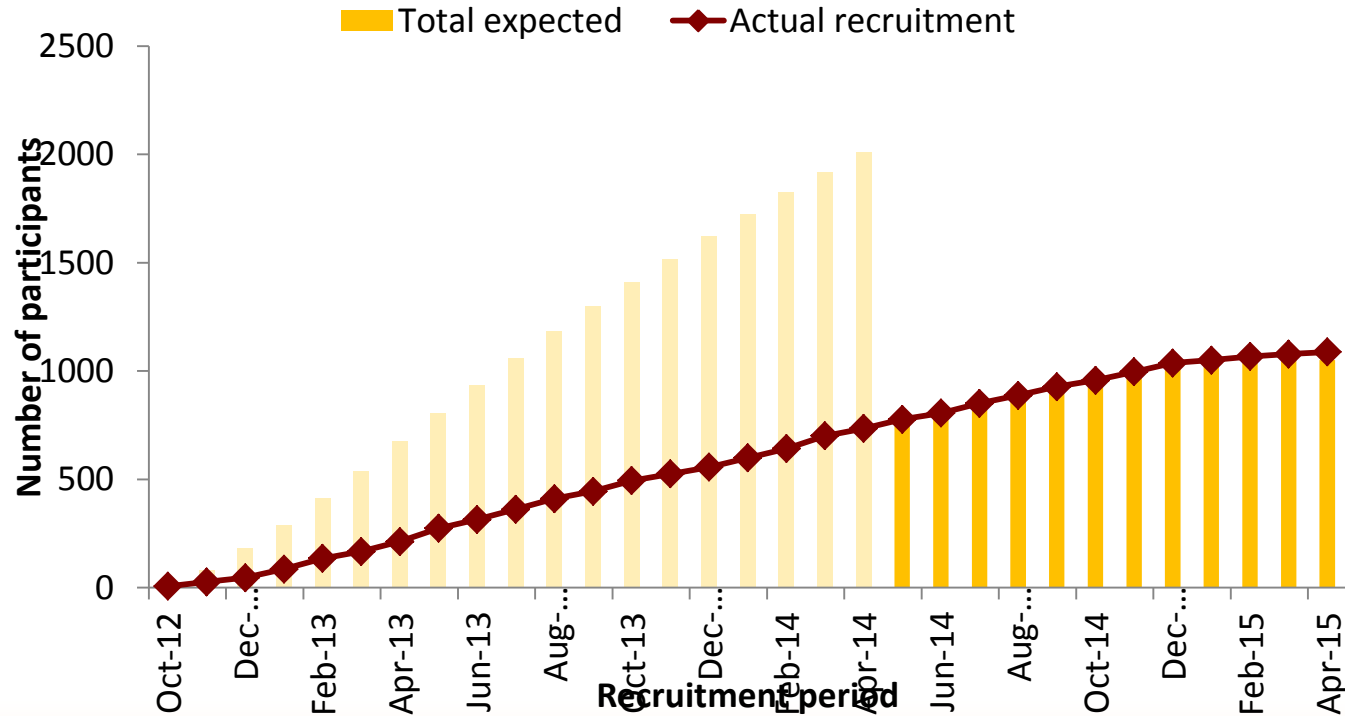
1. Expert health professional review
 - Including specific expertise in key areas, e.g. fertility, delay in diagnosis, patient choice
2. Expert patient review
 - Focus groups
 - Cognitive interviews

(Taylor et al. 2015 HQLO)



So how did we do?

Recruitment to the Cohort

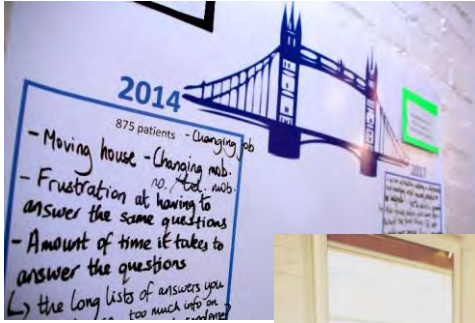




Focus on retention – the evidence

- Accurate contact information
- Study specific logo
- Newsletters, cards
- Incentivisation
- Contact with study dedicated staff
- Reminders before next participation
- Multiple options for data collection
- Stable contact details
- Flexibility in participation
- Certificates of participation/thanks
- Study dedicated phone support line

What else could we do?



- Enhanced method of tracing
- Revised website, including information about the study team, photographs of previous workshops, publications, conference presentations, and posters
- Infographic postcard with key emerging findings
- Personalised letter to participants before Wave 5
- Additional guidance to the telephone interviewers

(Taylor et al. 2017 JAYAO)



Conclusions

- Young people perceived as being 'vulnerable', hard to reach, hard to research
- Higher rate of participation and retention than other studies in TYA with cancer
- Why?



Reflection of the process

- Value of involving young people
 - Could they have been more involved?
- Survey content reflects experience
- Additional methods of administration
 - Paper versions, through an app?
- Method of tracing young people
 - Reduce the 'loss to follow-up'
 - Enable more frequent contact



QUESTIONS

This presentation presents independent research funded by the National Institute for Health Research (NIHR) under its Programme Grants for Applied Research Programme (Grant Reference Number RP-PG-1209-10013). The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health.



uclh.brightlight@nhs.net



www.brightlightstudy.com



0741 555 7668



@bR1GhTLiGhT

Using Multiple Sensory Communication and Interview Methods (MSCIM) for researching experiences of people with deafblindness

Dr Michelle Evans

Become what you want to be



**London
South Bank
University**

EST 1892

Session outline

- Aim of the presentation
- Background to the study
- Explanation of deafblindness and Usher syndrome
- Consideration of Multiple Sensory Communication and Interview Methods (MSCIM)
- How Multiple Communication and Interview Methods (MSCIM) can be developed further

Become what you want to be



**London
South Bank
University**

EST 1892

Aim of the presentation

To reflect on the benefits of using multiple sensory communication and interview methods (MSCIM) when conducting research with people who have communication differences.

Become what you want to be



**London
South Bank
University**

EST 1892

Background to the study

- This qualitative study entitled ‘Usher syndrome: A phenomenological study of adults across the lifespan’ aimed to develop an understanding of the experiences of, diagnosis of, and living with, Usher syndrome, from the perspective of adults in England.
- Twenty males and females with Usher syndrome, aged 18-82 years, were interviewed using MSCIM which is an acronym for ‘Multiple Sensory Communication and Interview Methods’ and was used to “foster research engagement through participant led communication and interview methods” (Evans 2016 p1)

Become what you want to be



**London
South Bank
University**

EST 1892

Deafblindness

- Persons are regarded as D/deafblind if they have a degree of combined visual and auditory impairment resulting in problems of communication, information and mobility (Deafblind Services Liaison Group, 1993).
- Although there are general definitions for people who experience D/deafblindness, each individual's experience will be unique to them (Evans and Whittaker 2010, Williams and Evans 2014), therefore Multiple Sensory Communication and Interview Methods (MSCIM) are essential.
- Usher syndrome is a rare inherited disease that is a leading cause of deafblindness (Genetic Alliance UK 2012) there are different types of Usher depending on extent of d/deafness at birth and progression.

Become what you want to be



**London
South Bank
University**

EST 1892

Multiple Sensory Communication and Interview Methods (MSCIM)

- My professional role as a sensory worker working with people who were D/deaf/D/deafblind and visually impaired: Natural for a service user to choose their interview and communication method, this participant led approach was applied during my research.
- Chosen **communication methods** included: visual frame British Sign Language, deafblind manual, clear speech and written word, and were used with **interviews** conducted face to face, via email, telephone and Skype.

Become what you want to be



EST 1892

**London
South Bank
University**

Table showing MSCIM choices

Participant	Interview method	Communication choice	Number of contacts
Adam	Face to Face/Email	Clear speech, visual frame BSL, Written communication	3
Ben	Face to face	Clear speech	1
Carl	Email	Written communication	3
Debra	Face to face	Visual frame BSL, Hands on BSL, Deafblind Manual	1
Eve	Face to face	Visual frame BSL, Written communication	1
Fred	Skype no video	Clear speech	1
Gareth	Telephone	Clear speech	1
Harry	Email	Written communication	2
Iris	Email	Written communication	2
Jeff	Skype with video	Clear speech	1

Table showing MSCIM choices

Participant	Interview method	Communication choice	Number of contacts
Kate	Telephone	Clear speech	1
Len	Telephone	Clear speech	1
Monica	Face to Face	Clear speech	1
Nora	Email	Written communication	2
Oliver	Email	Written communication	1
Pam	Telephone/Email	Clear speech, Written communication	2
Quentin	Telephone	Clear speech	1
Ruth	Telephone	Clear speech	1
Sara	Telephone	Clear speech	1
Tia	Email	Written communication	1

Multiple Sensory Communication and Interview Methods (MSCIM)

- Some participants selected a combination of MSCIM within one interview (Debra).
- The use of MSCIM provided a flexible and individualized approach that enabled participants to share their sensitive experiences, resulting in rich data and greater awareness of what life is like to live with Usher.

Become what you want to be



**London
South Bank
University**

EST 1892

Multiple Sensory Communication and Interview Methods (MSCIM)

- Choice of communication and interview methods were offered at all points of contact with the participants, and the participant information sheet offered participants the choice to communicate in their preferred communication methods
- Participant choice was paramount with regard to interview methods.
- Some participants chose their method and maintained that position (Len, Ruth, Sara – telephone) while other participants changed their mind (Pam – from email to telephone) if the initial choice was not felt to be comfortable choice.

Become what you want to be



**London
South Bank
University**

EST 1892

Multiple Sensory Communication and Interview Methods (MSCIM)

- Participants selected their communication and interview method based on their individual sensory need. For example Debra's sight and hearing loss was significant, therefore her communication choices included: Visual frame BSL, Hands on BSL, Deafblind Manual. Debra's choice of interview method was face to face because that was what she felt comfortable with because of her unique sensory needs.
- Whereas people whose preferred communication method was clear speech appeared to have more choice in relation to interview methods, for example Jeff chose Skype video on, Kate chose telephone, Monica chose face to face, Tia chose email and Fred chose Skype no video

Become what you want to be



**London
South Bank
University**

EST 1892

Multiple Sensory Communication and Interview Methods (MSCIM)

- Two participants (Debra, Eve) chose to have a person of their choice present at their interview – impact for participant (more relaxed, richer data), impact on me as a researcher (contributed to trustworthiness).
- Use of voiceover (where a hearing person interprets, using clear speech the comments made by the person using the visual form of communication) contributed to trustworthiness as having access to both audio and visual recordings of the interview enabled the researcher to cross-reference and ensure the interview content was truthful.

Become what you want to be



**London
South Bank
University**

EST 1892

Power dynamics when using MSCIM and the importance of reflexivity

- Power dynamics were reduced – I conducted all my own interviews and I was not always communicating in my first language, as highlighted in the example of Debra (82yrs), or choosing the communication or interview method
- Process of reflexivity or “turning your gaze to the self” (Shaw, 2010 p234) was essential and raised awareness of the impact of the research on the participants

Become what you want to be



**London
South Bank
University**

EST 1892

Future use of MSCIM

- Although, MSCIM was used to conduct interviews with people with sensory needs, it has significant potential for future use, as highlighted in my article ‘Empowering people experiencing Usher syndrome as participants in research’ because MSCIM can apply across a variety of settings that require “flexibility, adaptability, and the use of multiple methods” (Evans 2016 p1).
- MSCIM would be useful for people who experience other sensory differences (visual impairment/Deafness), physical disabilities or where English is not the person’s first language (Evans 2016)

Become what you want to be



**London
South Bank
University**

EST 1892

Future use of MSCIM continued

- Using technological tools such as Skype enables participants to maintain a degree of anonymity if they wish to, as they can be involved in research with the video on or off (Evans 2016).
- MSCIM has a wide range of practical uses, for example, in police/job centre interviews and health consultations (Evans 2016).
- Using MSCIM would enable people to feel more comfortable and empowered in what could be a stressful situation (Evans 2016).
- MSCIM would also be useful when conducting research with participants in hard to reach areas such as prisons, remote geographical areas or international research collaboration (Evans 2016).

Become what you want to be



EST 1892

**London
South Bank
University**

Conclusion

- Multiple Sensory Communication and Interview Methods (MSCIM) has already proved a useful innovative tool when conducting research with people with sensory requirements, however, it has the potential for innovative future use as considered.
- Research being participant led as opposed to solely researcher led empowers participants and enables them to feel more comfortable and willing to share their experiences in what could be a very sensitive experience.
- Finally, considering participant choices could lead to greater willingness for participants to contribute to research in the future.

Become what you want to be



**London
South Bank
University**

EST 1892

References

- Deafblind Services Liaison Group (1993) *Coming together - proceedings of a seminar concerning the formation of a United Kingdom coalition of deafblindness (Nov 26th 27th, 1993)* Birmingham: Sense.
- Evans, M (2017) Empowering people experiencing Usher syndrome as participants in research *British Journal of Social Work*, Vol. 47 (8) pp 2328-2345.
- Evans, M and Whittaker, A (2010) *Sensory Awareness and Social Work* Exeter: Learning Matters.
- Genetic Alliance UK (2012) available at: <https://www.geneticalliance.org.uk/> Accessed: 24/02/2017.
- Moller, K, Eriksson, K, Sadeghi, A, M, Moller, C and Danermark, B (2009) Long-term ophthalmic health care in Usher Syndrome type I from an ICF perspective *Disability and Rehabilitation* Vol. 31(15) pp1283-1292.

Become what you want to be



EST 1892

**London
South Bank
University**

References

- Pennings, R, Deutman, A, Fields, R, Kimberling, W, Huygen, P, Cremers, C (2003) Usher Syndrome type III can mimic other types of usher syndrome *Ann Otol Rhinol Laryngol* Vol. 112 pp525-530.
- Sadeghi , M, Cohn, E, Kelly, W, Kimberling, W, Tranebjoerg, L, Moller, C(2004) Audiological findings in Usher Syndrome types IIa and II (nonIIa) *International Journal of Audiology* Vol. 43 pp136-143.
- Shaw, R (2010) Embedding reflexivity within experiential qualitative psychology, *Qualitative Research in Psychology*, 7(3), pp. 233-243.
- Williams, P and Evans, M (2013) *Social Work with People with Learning Difficulties* London: Sage/Learning Matters.

Become what you want to be



EST 1892

**London
South Bank
University**

Any questions?

Contact details

Dr Michelle Evans

London South Bank University

evanm9@lsbu.ac.uk

Become what you want to be



**London
South Bank
University**

EST 1892



Accessing the 'hidden voices': Experiences of recruiting from the Bangladeshi community with ankylosing spondylitis.

Debbie Chagadama

Lead Nurse (Musculoskeletal Service)



Outline:

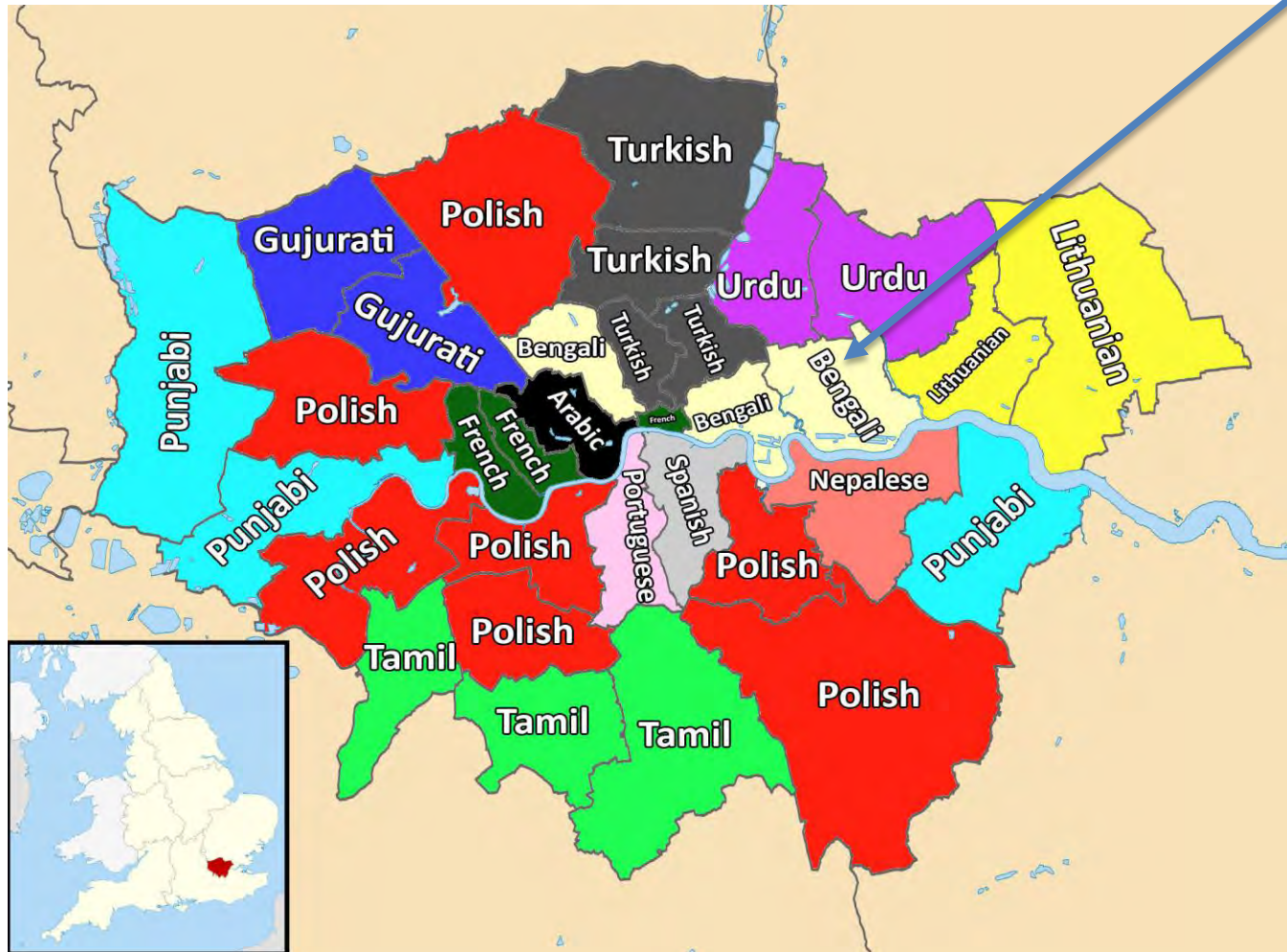
- Background
- **Challenges in recruiting 'hard-to-reach' groups**
- Methodology
- Recruitment process
- Findings



Aims of study & Background:

- An exploration of lived experience of health-related quality of life in Bangladeshi people with Ankylosing Spondylitis (AS)

- AS is an inflammatory systemic rheumatologic condition often resulting in severe disability



London Boroughs by language most commonly spoken other than English (Census 2011)



Background cont.

- Largest ethnic group making up 34% of the whole population in Tower Hamlets (7% Black; 3% Chinese; 2% Indian & 4% other).
- Widespread deprivation, hard to reach group, high incidence of chronic health problems; poor educational qualifications; significant number do not speak English as a first language; under diagnosis of certain conditions; there are barriers to accessing healthcare services.
- Audit of 250 patients with AS on biologics showed 38.7% had Bangladeshi listed as the ethnic origin
- Limited research into difficulties faced by Bangladeshi people with AS in UK



Background :

- Researchers struggle to access, engage and retain these groups ('hard-to reach' or 'hidden')
- Mistrust in research or researchers
- Cultural beliefs prohibiting participation
- Potential harm or exploitation
- Gatekeepers unaware of research/ restricting access
- Rigid inclusion criteria
- Low literacy
- Cost of involving interpreters/translation



Methodology

- Planning stage
- Familiarising with the Bangladeshi culture and community
- Gaining access
- Gatekeepers & key community figures (to mediate and partially validate access to participants)
- Clarifying roles in the process (researcher & participants)
- Adhering to ethical guidelines to ensure minimal risk & gain cooperation of participants.

Step 1

Raising awareness

Step 2

Developing relationships with the community

Step 3

Building Trust & Rapport

Step 4

Culturally tailored resources and materials

Step 5

Involvement & mobilisation of key community figures

Step 6

Demonstrate respect & knowledge of culture, traditions & ethics

Recruitment process



Recruitment strategies

- Culturally and linguistically appropriate
 - ✓ Engaging with community gatekeepers
 - ✓ Engaging with direct care teams in the clinics
 - ✓ Translating materials to Bengali
 - ✓ Training and using interpreters

Results:



- Gatekeepers played an important role in the recruitment process
- Interpreters were used as research partners
- Relevant documents were translated to Bengali
- Used direct care teams of nurses and doctors in the AS clinics to make initial approach to participants
- Recruited 20 participants over a 7 month period (males n=15) and (females n=5)
- 6 interviews were conducted in Bengali . Had 109 pages of qualitative interview data to analyse



Summary:

- Obtained rich & meaningful data which has highlighted the ‘hidden voices’ & experiences of the Bangladeshi participants.
- Participants spoke openly and in-depth about:
 - Struggling to gain a diagnosis
 - How the condition affects them on a day to day basis
 - How they were managing with the illness
- Through this research the ‘hidden voices’ of the Bangladeshi patients are being heard & will inform healthcare practice

References



- Hussain-Gambles, M. Atkin, K. & Leese, B. (2006) South Asian participation in clinical trials: the views of lay people and health professionals. *Health Policy*; 77:149- 65
- Jolly, K., Lip, G.Y., Taylor, R.S. et. al (2005) Recruitment of ethnic minorities patients to a cardiac rehabilitation trial: the Birmingham Rehabilitation Uptake Maximisation (BRUM) study[ISRCTN72884263]. *BMC Med Res Methodol*; 5:18
- Nichols-Casebolt, A. & Spakes, P. (1995) Policy research and the voices of women. *Social Work Research*, 19(1): 49-55
- Nilaweera, I., Doran, F., & Fisher, J. (2014) Prevalence, nature and determinants of post-partum mental health from South Asian to high-income countries: A systematic review of the evidence. *Journal of Affective Disorder*; 166: 1271-83
- Oakley, A., Wiggins, M., Turner, H. et al (2003) Including Culturally Diverse Samples in Health Research: A Case Study of an Urban Trial of Social Support. *Ethnic Health*; 8:29
- Office for National Statistics (ONS) 2012 Ethnicity & National Identity in England and Wales, 2011, ONS. London.
- Sheikh, A., Halani, L. Bhopal, R. et. al (2009) Facilitating the recruitment of minority ethnic people into research: Qualitative care study of South Asians and asthma. *PLoS Med*; 6: e1000148

Thank you



Contact: Debbie.Chagadama2@bartshealth.nhs.uk



London
South Bank
University

EST 1892

.....
London Doctoral
Academy

The Lived Experience of Dementia within Individuals of Black ethnicity: the interview process

Dr. Tiritega Perfect Mawaka
@MawakaP



Dementia and ethnicity..

- There are nearly 25000 people living with dementia from Black and Minority Ethnic groups in England and Wales.
- Black and Minority Ethnic (BME) groups are more at risk of developing Vascular Dementia and experience a higher rate of young-onset dementia (≤ 65 years) compared with the majority ethnic White British population.
- BME people living with dementia in the UK, are underrepresented in health services, they receive a diagnosis later in their disease progression and are less likely to access dementia services.



Research questions

- What is the lived experience of the individual of Black ethnicity living with dementia?
- How does the individual of Black ethnicity living with dementia describe their experience and everyday lives?



Methodology:

- Interpretive phenomenology based on the work of Heidegger (1927) was used to explore the experiences of six participants.
- A series of 3 semi- structured interviews
- Audio recorded
- Transcribed verbatim
- Thematic data analysis was conducted, using a framework by Braun & Clarke (2006).



The interview process...

Inclusion criteria

1. Clinical diagnosis of dementia.
2. Black ethnicity.
3. Reside within 4 East London health sector and receive dementia health care services from Mental Health Foundation Trust.
4. Has a relative/friend who is willing to act as a Consultee
5. Has the capacity to understand the information sheet and is competent to give informed consent
6. Is willing to take part in the interview
7. Is able to communicate verbally and in English

Exclusion criteria

1. Consultee considers that taking part in an interview would be detrimental to the participant
2. Unable to take part in an interview due to current health condition or likely rapid deterioration
3. Does not have the capacity to understand the study information and is not competent to give informed consent
4. Cannot speak English
5. Cannot communicate verbally



Ethical Approval..

The NHS Research Ethics Committee requested clarification on several points mainly:

- The Committee recommend to the applicant to complete the training on how to identify mental capacity.
- The Committee asked to applicant to confirm what procedure is in place to deal with participants who become distress.
- The Committee sought clarification on who will be assessing the capacity of the patient with regards to the Mental Capacity Assessment, and will this be done at every new interaction?



Semi-structured interviews...

- 1st interview
- Life before dementia-memories of setting in the UK, Jobs and work, Family, Culture and Community
- 2nd interview
- Journey to diagnosis-signs, symptoms of dementia, access to health services
- 3rd interview
- Explores areas that were not previously explored



Consent...

- Participant-Informed Consent was an ongoing process

Consultees...

- Use of Consultees- friend/relative
- Information sheets/consent forms for Consultees
- Time to build rapport with both the participant and Consultee



Use of language

- Use of the term dementia
- Cultural expression: e.g participant referring to researcher as *'my daughter'*
- Participants required constant prompts
- Participants at times got confused



Conclusion....

- This study has shown that it is possible to interview participants living with dementia, to capture their stories with support from Consultees. In this study the researchers clinical experience proved to be a strength in supporting the interview process.



Acknowledgements

London South Bank University Supervisors

Study participants

Funders of the Mary Seacole Leadership Awards





London
South Bank
University

.....
London Doctoral
Academy

Questions?

Contact: tiritega.mawaka@nhs.net

@MawakaP



Any final questions?

Thank you for attending our
symposium

