Institution: Brunel University London		
Unit of Assessment: 3 Allied Health Professions, Dentistry, Nursing and Pharmacy		
Title of case study: Improving services for Electrically Powered Indoor/Outdoor Chair (EPIOC) users		
Period when the underpinning research was undertaken: 2003-2017		
Details of staff conducting the underpinning research from the submitting unit:		
Name(s):	**Role(s) (e.g. job title):**	**Period(s) employed by submitting HEI:**
Lorraine De Souza	Professor	09/1981-01/2019
Period when the claimed impact occurred: January 2014 to Dec 2020		
Is this case study continued from a case study submitted in 2014? No		

1. Summary of the impact (indicative maximum 100 words)

Brunel research has supported a paradigm shift from the provision of EPIOCs as simple mobility aids to tools that facilitate rehabilitation, independence and the participation of severely disabled individuals in society. It has informed public policy, provided resources for wheelchair users and purchasers and enhanced international clinical guidelines impacting 1,200,000 UK, 1,700,000 USA wheelchair users and an estimated 131,800,000 needing wheelchairs worldwide since 2014. These major impacts have improved EPIOC prescription for people growing up and growing old with enduring disability. As a result of this research effective policies have been developed, professional practice has been enhanced and more appropriate assessment and prescription is provided to EPIOC users.

2. Underpinning research (indicative maximum 500 words)

Professor De Souza and clinical colleagues have a significant record of research into improving services for EPIOC users. This research, led by Prof De Souza, has influenced policy, practice and provision by emphasising that EPIOCs should be prescribed for rehabilitation and social participation purposes and not just as a mobility device. It emphasised that changing needs across the lifespan for those with complex and additional health conditions (comorbidities) must be considered alongside individuals' primary diagnosis. The findings stressed that the impact of not meeting individuals' needs causes life impoverishing complications, like scoliosis and contractures, which extend hospitalisation and treatments.

An estimated 131,500,000 people worldwide need wheelchairs. Services are challenged to achieve best practice and cost effectiveness that matches the current/future health condition of individuals, their requirements and preferences with chair and seating technologies that payers can support. Brunel research (REF1) uniquely demonstrated that provision of an EPIOC significantly improved users' QoL as well as mobility, pain and discomfort. They adapted and developed the EuroQoL (EQ5D) to enable people with severe disabilities to report their QoL before and after EPIOC provision (REF1). Prior to this there was no existing measure available to determine QoL in that group. The study underlined that QoL was an essential health improvement facilitated by EPIOCs.

This research (REF2) explored the views of young people using EPIOCs demonstrating that young people with severe disabilities had similar needs and ambitions as their able-bodied peers. They not only relied on an EPIOC for mobility, but importantly it impacted social inclusion, providing opportunities to build relationships with their peers and to facilitate overall development including enabling entry to the world of work. Users particularly valued the independence and privacy from parents that an EPIOC provided. Until these findings, EPIOCs had only been prescribed as a mobility aid; this research evidenced the equally important benefits derived from enhanced social inclusion through development opportunities afforded to children for whom EPIOCs may enhance independence and facilitate participation in family, school, and community life.

Evidencing the clinical therapeutic use of EPIOCs, Frank and DeSouza (REF3) examined pain experienced by users. They differentiated pain due to EPIOC inadequacies and pain due to underlying diagnoses and co-morbidities, concluding that problematic pain required examination, and was manageable through medical interventions, or by enhanced use of EPIOC functions and seating.

DeSouza and Frank 2010 (REF4) DeSouza and Frank 2017 (REF5) and Frank and DeSouza 2016 (REF6) focussed on the therapeutic role of EPIOC for users with MS, rare diseases and CP across the age span highlighting issues relevant to ageing with these diagnoses, namely, mobility, pain, fatigue, and comorbidity, exploring deterioration due to diagnoses and inadequate long-term management. Findings emphasised the occurrence of avoidable complications resulting from inadequate wheelchair provision which had consequences for provision with regard to type of chair and seating. These studies underlined the essential therapeutic role of EPIOCs and how provision is influenced by progressive neuromuscular impairments of the conditions, comorbidities and disorders related to long-term disability. De Souza and colleagues recommended a holistic model of rehabilitation rather than a disease management orientated approach.

3. References to the research (indicative maximum of six references)

REF1 Davies A, De Souza L, Frank, AO. Changes in the quality of life in severely disabled people following provision of powered indoor/outdoor chairs, Disability and Rehabilitation: Assistive Technology, 2003; 25(6): 286 – 290. http://dx.doi.org/10.1080/0963828021000043734

REF2 Evans S, Neophytou C, De Souza L, Frank AO. Young people's experiences using electric powered indoor - outdoor wheelchairs (EPIOCs): Potential for enhancing users' development? Disabil Rehabil. 2007; 29:1281–94. http://dx.doi.org/10.1080/09638280600964406

REF3 Frank AO, De Souza LH, Frank JL, Neophytou The pain experiences of powered wheelchair users. Disability and Rehabilitation 2012; 34(9), 770-778. DOI: 10.3109/09638288.2011.619620

REF4 Frank AO, Neophytou C, Frank J L and De Souza L H Electric Powered Indoor/Outdoor Wheelchairs (EPIOCS): users' views on family, friends and carers. Disability and Rehabilitation: Assistive Technology 2010; 5: 327-338.

REF5 Frank AO, De Souza LH Problematic clinical features of children and adults with cerebral palsy who use electric powered indoor/outdoor wheelchairs: A cross-sectional study, Assistive Technology 2017; 29:2, 68-75. DOI: 10.1080/10400435.2016.1201873

REF6 De Souza LH, Frank AO. Rare diseases: matching wheelchair users with rare metabolic, neuromuscular or neurological disorders to electric powered indoor/outdoor wheelchairs (EPIOCs). Disability and Rehabilitation 2016; 38(16): 1547-56. DOI: 10.3109/09638288.2015.1106599

4. Details of the impact (indicative maximum 750 words)

The situation for wheelchair users with complex and changing needs has been called "intolerable", especially for children. Clinical provision and care has been enhanced as a result of impacts of this research on policy through evidence regarding the value of EPIOCs in enabling employment, education, social integration, health status and improved QoL allowing users to participate more fully in society, and enhancing personal comfort and lowering their risk of serious complications from EPIOC use.

Using this research (REF1), the NHS warned that wheelchairs poorly matched to users' needs adversely affected activities, participation, lifestyle goals and health status, adding to cost and/or non-use or abandonment of the wheelchair (E1). Brunel research outputs underpinned the case for growing support, internationally for providing EPIOCs to encourage social and community interaction. They emphasised that driving assessment including functional and cognitive abilities and education on safety were essential for EPIOC users; a recommendation from this research into young EPIOC users. Brunel research (REF1, REF2, REF4) was used to underpin key targets for health service improvements and core service delivery standards for therapists who support people with disabilities, benefiting 1,200,000 potential chair users in the UK and an estimated 72,000 potential users in NSW Australia (E2).

Impacts on practitioners and services internationally

Professional standards, guidelines and evidence-based sources have been shaped by the research

By transforming understanding of the importance of EPIOCs for children's development and successful transition to independence in adulthood, this evidence has broadened assessment to include provision based on the social development needs of children and young adults, not just their mobility needs. Internationally, practitioners have improved evidence-based guidelines and recommendations to enhance the quality of their professional practice.

This research has been used internationally to recommend that for children with inefficient mobility, EPIOCs enhance independence and facilitate participation in family, school, and community life. Direct use of study REF3 highlighted that to enhance EPIOC use without contributing to problematic posture and pain, supportive seating, powered seating functions and adequate suspension are important features to consider in prescription (E3, E8). Brunel research highlighted widespread debilitating suffering caused by pain (E3) and that EPIOC users related their pain to underlying medical conditions and to improperly configured wheelchairs. EPIOC users opined that wheelchair tilt functions can be used to manage pain/discomfort. This research informed influential position statements to support the application of seat functions to assist clinicians in decision-making and justifying funding (E4).

Brunel research (REF2) underpinned advice on when children should start using power mobility. The evidence was used to recommend that early utilization of EPIOCs for children with mobility limitations enhances independence, improves development in multiple areas, and enables children to grow to become productive and integrated members of society (E5, E8).

Expert international consensus now endorses the therapeutic use of wheelchairs beyond mobility assistance. Using this research (REF6), international recommendations advocate short

orthoses for daytime use to prevent ankle deformity and prolong gait ability and emphasise that correctly adapted wheelchairs can prevent skin ulcers and slow scoliosis progression thereby counteracting life-threatening complications for children with muscular dystrophy (E6). Drawing directly on these findings (REF2) an international consensus group published clinical practice guidance for powered mobility in children of different ages, needs, and abilities. Recommendations based on these publications highlight the importance of EPIOCs in enhancing independence and facilitating participation in family, school and community life and that enhancing EPIOC use without contributing to problems of posture and pain, supportive seating, powered seating functions, and adequate suspension are essential features to consider in chair prescription (E7).

The research on children has been utilised by clinicians for the prescription of EPIOCs and to develop and provide hand-outs for advanced training and safety for different types of child learners and to inform and support their parents (E8). One of these hand-outs has recently been translated into Norwegian (E9) further illustrating the need internationally for evidence-based information to support child EPIOC users and their parents/carers.

Impacts on commercial companies

Material provided by companies for chair prescribers, users, payers and other purchasers has been informed by this Brunel research and used as part of the justification for costs. The research (REF5) has provided evidence-based information to prescribers and purchasers of wheelchairs, demonstrating that appropriate seating interventions, alongside competent assessment, can reduce pain and suffering, but at a financial cost which is justifiable by the enhanced wellbeing of chair users (E9). Brunel research (REF4) changed funding decisions in Canada from the provision of power tilt and recline chairs for pressure relief to the provision tilt-in-space features that give users the ability to autonomously control comfort, rest and pain reduction (E10). Brunel research has changed perceptions of the role of EPIOCS from mobility aids to enhancing the engagement of severely disabled adults and children in society. It has contributed to developing the market and international clinical guidelines impacting 1,200,000 UK, 1,700,000 USA wheelchair users and approximately 131,800,000 people needing wheelchairs worldwide.

5. Sources to corroborate the impact (indicative maximum of 10 references)

E1 “Right Chair, Right time, Right Now” NHS Improving Quality Publication date: November 2014
E2 The NSW Government Family and Community Services 24-hour Positioning Guide (including seating and wheeled mobility): Practice Guide for Occupational Therapists and Physiotherapists who Support People with Disabilities. Jan 2016
E3 Best Practice Guidelines (BPG7): Clinical practice considerations for the use and introduction of powered mobility with children 2014.
E4 RESNA Position on the Application of Tilt, Recline, and Elevating Leg rests for Wheelchairs Literature Update 2015
E5 RESNA Position on the Application of Power Mobility Devices for Pediatric Users-Update 2017
E6 Brazilian consensus on Duchenne muscular dystrophy. Part 2: rehabilitation and systemic care. https://doi.org/10.1590/0004-282X20180062
E7 Livingston R and Paleg G. Practice considerations for the introduction and use of power

mobility for children. Developmental Medicine & Child Neurology 2014, 56: 210–222. http://onlinelibrary.wiley.com/doi/10.1111/dmcn.12245/pdf
E8 Correspondence from clinicians: Livingston and Martelli
E9 Pain In People Using Wheelchairs M Lange Seating Dynamics www.wheelchair-experts.in/category/mobility-health-tips/
E10 Putting Evidence into Practice for Power Positioning. Sheilagh Sherman, Sunrise Medical. http://www.sunrisemedical.ca/dealer-clinician-tools/education-in-motion/clinical-corner/february-2017/putting-evidence-into-practice-for-power-positioning