

Institution:	GOLDSMITHS, UNIVERSITY OF LONDON
Unit of Assessment:	04 PSYCHOLOGY, PSYCHIATRY & NEUROSCIENCE
Title of case study:	Enhancing quality of life after acquired brain injury
1. Summary of the impact (indicative maximum 100 words)	

Powell’s work focuses on outcomes after traumatic brain injury. In 1995 she established an innovative community-based multidisciplinary neurorehabilitation service – the Outreach Team – and evaluated it via a randomised controlled trial. The positive findings have informed policy and service developments internationally. In parallel, she developed a new outcome instrument [the BICRO] to evaluate psychosocial functioning; this is now used by clinicians in 10+ countries. The BICRO informed the subsequent development and validation of a cross-cultural instrument for assessing quality of life after brain injury [the QOLIBRI]; Powell was a member of the Steering Group which directed the complex international collaborative QOLIBRI project. The QOLIBRI is now available in many languages, and has been fully validated in six. There are 400+ registered users in over 35 countries, more than 200 being clinical service providers; it is a formally recommended tool for public health services in Finland and the US; and it is being used as an outcome measure in numerous treatment evaluations and prospective studies worldwide.

2. Underpinning research (indicative maximum 500 words)
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Traumatic brain injury [TBI] causes long-term disability with adverse social, psychological and economic consequences. Rehabilitation seeks to optimise independence and social participation in order to reduce long-term care needs and enhance quality of life [QoL]. Powell, a clinical neuropsychologist, has held a full-time academic post at Goldsmiths since 1994, progressing from lecturer to professor. Over this time she has worked collaboratively with clinicians and TBI patients to develop and evaluate treatments and new outcome measures.

In 1998 she and a neurologist [Greenwood] were awarded competitive Dept of Health funding to design and establish a new ‘model’ neurorehabilitation programme for TBI patients living in the community. Multidisciplinary and psychology-led, the **Outreach Team** is based at Homerton Hospital in North-East London. A comparative economic evaluation of the 11 projects funded under this initiative was conducted by an independent health economics group at Warwick [Stilwell et al, 1999]. In parallel, a more focused and robust randomised controlled trial [RCT] of the Outreach service was carried out by Powell and Greenwood, funded by a 3-year MRC grant [1995-98]. This demonstrated superior outcomes in Outreach-treated patients relative to those receiving ‘treatment as usual.’^[1] Still the only published RCT of community-based provision for TBI, it is widely cited in clinical and research literature and in national policy documents including the Department of Health’s National Service Framework for Long Term Conditions (2005) and NICE guidelines for the management of chronic conditions such as multiple sclerosis (2005).

Evaluation of TBI interventions has been constrained by a paucity of instruments sensitive to the complex and heterogeneous sequelae of brain injury. In the context of the above RCT, Powell and colleagues developed and validated the **Brain Injury Community Rehabilitation Outcome (BICRO-39) scales**.^[2] This indexes patients’ independence in personal care, mobility, and self-organisation; the extent of their socialising and productive employment; and aspects of psychological wellbeing which are particularly affected by TBI. A series of studies have demonstrated its good psychometric properties including sensitivity to TBI-related problems,^[2] to recovery over time,^[3] and to treatment effects.^[1]

The BICRO was influential in the construction of a new measure for assessing quality of life [QoL] after TBI – the **QOLIBRI**. QoL is recognised as a key dimension of outcome against which clinical interventions should be evaluated, but existing generic tools such as the WHO-QoL lack sensitivity to the very specific problems emanating from complex conditions such as TBI. In 2002 Powell was part of a new international ‘workforce’, comprising neurologists and neuropsychologists from more than ten countries who convened to develop a cross-cultural TBI-specific instrument which would be sensitive to the cognitive, affective and behavioural impairments (e.g., memory problems, personality changes) often characterising TBI. She was elected to the Steering Group which directed the ensuing 10-year project to construct and validate the new cross-cultural measure, and she and

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Greenwood were awarded an NHS R&D grant to gather data for the UK sample.

The QOLIBRI drew some items from existing outcome measures, including the BICRO, and was developed in six European languages concurrently, prior to being validated by teams based in over ten countries.^[4, 5] It requires respondents to rate (a) their ‘satisfaction’ with their cognition, sense of ‘self’, daily life/autonomy, and social relationships, and (b) how much they are ‘bothered’ by emotional/physical problems, and can be completed even by severely impaired patients.

It has subsequently been translated and validated in several other languages. An initial long version was administered to >1500 patients; psychometric analyses yielded shorter (37-item and 6-item) versions that were validated in a new sample of 900+ participants. The two current versions have similar reliability and sensitivity, suiting them to a range of contexts and needs.

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

The international quality (2* or higher) of this research is evidenced through the publication of key findings in highly selective and rigorously peer-reviewed international journals, and the high citation rates of several of the articles.

1. **Powell J**, Heslin J, Greenwood R (2002) Community-based rehabilitation after TBI: A randomised controlled trial. *J Neurol Neurosurg Psychiatr*, 72, 193-202. DOI: 10.1136/jnnp.72.2.193 [journal article; 137 citations].
2. **Powell J**, Beckers K, Greenwood R (1998) Measuring progress and outcome in community rehabilitation after brain injury with a new assessment measure: the BICRO-39 scales. *Arch Phys Med Rehabil*, 79, 1213-1225. DOI:10.1016/S0003-9993(98)90265-9 [journal article; 75 citations].
3. **Powell J**, Kitchen N, Heslin J, Greenwood R (2004). Psychosocial outcomes at 18 months after good neurological recovery from aneurysmal subarachnoid haemorrhage. *J Neurol Neurosurg Psychiatr*, 75(8): 1119–1124. DOI: 10.1136/jnnp.2002.000414 [journal article; 68 citations].
4. von Steinbuechel, Wilson, Gibbons, Hawthorne, Höfer, Schmidt, Bullinger, Maas, Neugebauer, **Powell**, von Wild, Zitnay, Bakx, Christensen, Koskinen, Formisano, Saarajuri, Sasse, Truelle (2010) Quality of Life after Brain Injury (QOLIBRI) – Scale Development and Metric Properties. *J Neurotrauma*, 27,1167-85. DOI: 10.1089/neu.2009.1076 [journal article; 36 citations].
5. von Steinbuechel, Wilson, Gibbons, Muehlan, Schmidt, Schmidt, Sasse, Koskinen, Sarajuuri, Höfer, Bullinger, Maas, Neugebauer, **Powell**, von Wild, Zitnay, Bakx, Christensen, Formisano, Hawthorne, Truelle (2013). QOLIBRI Overall Scale: A brief index of health-related quality of life after traumatic brain injury. *J Neurol Neurosurg Psychiatr*, 83(11): 1041-7. DOI: 10.1136/jnnp-2012-302361 [journal article].

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

A. The Outreach Team: The RCT of this community-based rehabilitation programme, showing positive effects, continues to influence policy and service provision internationally. It remains a key point of reference in relation to publicly and privately funded healthcare/rehabilitation - for example:

- **USA:** The Agency for Healthcare Research and Quality (AHRQ) is mandated by Congress to carry out Clinical Effectiveness Reviews [CERs] which “*inform health plans, providers, purchasers, government programs, and the health care system as a whole*”. This RCT is one of a handful of studies judged sufficiently strong to feature in an on-going CER of postacute TBI rehabilitation.^[1]

Health insurers now fund cognitive rehabilitation after TBI, but not after other conditions, on the basis of the evidence base of which this RCT is a key part; the study is explicitly cited in the official 2013 Medical Policy documents of United Healthcare and Anthem Healthcare.^[2] The latter for instance states that “...*published data provides the most support for effectiveness of cognitive rehabilitation in individuals with TBI. For example, Powell and colleagues (2002)*...”

- **Canada:** A 2011 government-mandated evidence-based review informing national healthcare policy cites Powell’s study as the only Level 1 evidence that “*structured multidisciplinary rehabilitation in community settings can improve social functioning*.”^[3]
- **New Zealand:** The Accident Compensation Corporation, which provides universal comprehensive personal injury cover, cites the RCT in its 2011 Pragmatic Based Review which concludes that “*a multidisciplinary rehabilitation program appears to be the most effective approach*”

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to help people with TBI reintegrate into the community.” [4]

B. The BICRO scale: Over 40 hospitals, treatment centres and clinicians from across the world including the UK, USA, Canada, Australia, New Zealand, Japan, Israel, France and Germany have requested use of the BICRO. It is free to [download](#), subject to registration, and is being used extensively to evaluate outcomes at individual and service level.^[5]

One of the UK’s leading private providers of medico legal reports and rehabilitation funded through compensation awards, Rehab Without Walls [RWW], uses the instrument routinely to assess and report on progress: *“BICROs are done on formally taking on a new case, and at formal reviews (e.g. 6 monthly) thereafter ...This is a vital part of our quality assurance, and demonstrates our commitment to measure our effectiveness ...When I’m reviewing progress, BICRO scores give a very good anchor point against which to judge both current clinical status and proposals for further input.”* (Director of RWW ^[6]). RWW has approached Powell seeking the development of a paediatric version; preliminary work on this, collaboratively between RWW and Goldsmiths, has commenced.

C. The QOLIBRI: In the public domain for less than two years, the QOLIBRI is in heavy demand and available for [free download](#). Since its original validation in English, French, German, Dutch, Italian and Finnish it has been translated into numerous additional languages including Arabic, Chinese, Czech, Danish, Indonesian, Japanese, Malay, Norwegian, Polish, Portuguese, Spanish, and Russian. It has been separately validated in Australia [Hawthorne et al., 2011]; other validations are on-going.

On the 31/07/13 there were over 400 registered users in 35 countries across all continents. Of these, 34% were university-based, 60% clinically-based, c. 2% in voluntary support organisations such as Headway, and c. 3.5% in military rehabilitation facilities. It has also been downloaded by individual clinicians and TBI survivors. Registration information provided in order to access the instrument and reported in the database ^[7] evidences well over 200 rehabilitation centres, health authorities, and healthcare providers using it to inform treatment and/or evaluate outcomes. Examples of its diverse clinical and policy applications include:

- **Belgium**, DenAchtKanter: *“Every client has a personal support plan and we would like to have an idea in what measure their TBI influences their QoL. Once we have a better view, we hopefully will be able to make better objectives.”*
- **England**, Chase Park Rehabilitation Centre: *“To produce an outcomes document for commissioners of services, people with BI and their families.”*
- **New Zealand**, Abano Rehabilitation: *“To determine whether our clients are satisfied with their lives in our facilities and, if not, what we can do about it.”*
- **Norway**, Suunass Rehabilitation Hospital: *“To use pre, post and at follow-up to study whether improved executive functioning is related to improved mental health and QoL.”*
- **Pakistan**, Aga Khan University Hospital: *“To measure health care and personal costs of head injuries in motorcycle riders ... so that we can make a case for helmet regulation.”*
- **Scotland**, NHS Greater Glasgow: *“To compare QoL of young [TBI] adults living in nursing homes with [those] living in community and [with the] general population.”*
- **USA**, Krempels Centre: *“To determine if we are meeting our mission of improving the lives of people living with BI [brain injury].”*

It is now recommended for national use by the Finnish public health and social care network (TOIMIA) ^[8] and by a US Government/National Institutes of Health interagency group,^[9] and has been incorporated into numerous prospective or comparative clinical investigations. In the US the NIH Clinical Trials website ^[10] shows it being utilised in three treatment evaluations; and the *qolibrinet* database indicates its use in over 80prospective studies or randomised controlled treatment trials [RCTs] with projected samples of >200. Examples of studies going on across the world using it as a key outcome measure include:

- **Australia:** The Royal Perth Hospital is studying the prevalence and severity of symptoms and QoL after road traffic related TBI (n=450).
- **Finland:** An EU-funded project at Turku University Hospital is developing individual evidence-based diagnostics and treatment solutions to match treatments to clinical features [n=1000].

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- **Spain:** Barcelona's Vall d'Hebron University Hospital is evaluating a core dataset, including the QOLIBRI, for assessing outcome after moderate and severe TBI [n = 200+].
- **UK:** Two on-going projects in Cambridge include a prospective study of outcomes after mild TBI (n=1000); and an RCT of surgical interventions for acute subdural haematoma.
- **USA:** Defense and Veterans Brain Injury Centers [North Carolina, Washington State, Pennsylvania]: (a) a prospective evaluation of outcomes in 750 active duty members after concussion; (b) investigation of the chronic consequences of mild TBI in recent returnees of the Iraq and Afghanistan wars (n = 515); (c) development by the Office of Rehabilitation Services of a VA TBI-Toolbox with instruments for use by its polytrauma rehabilitation providers.
- **USA:** Tulane Institute of Sports Medicine: Effects of treatment for head trauma in >200 professional football players.

In 2011 the Eli Lilly pharmaceutical company awarded the QOLIBRI its annual Quality of Life prize, which recognises outstanding research achievements contributing to improving patients' QoL ^[11].

The QOLIBRI Society has been established to promote dissemination and research into factors affecting QoL after TBI; Powell is on the Board, and on 11/06/13 she organised and hosted (at Goldsmiths) a symposium/workshop directed principally at clinicians, and delivered by international speakers from the QOLIBRI taskforce. It was sponsored by the prominent law firm, Leigh Day, which believes that the QOLIBRI will be valuable in the medicolegal context, helping to quantify the effects of TBI and thus to inform the courts in relation to compensation payments ^[12]. The event, for which there was a registration fee, was attended by over 60 clinicians and service providers; the revenue is being used by the Society to facilitate future dissemination and training events. Many of the attendees have subsequently become members of the Society, and have registered their interest in contributing data from their services to a collaborative database to be used for normative and comparison purposes. The workshop will be replicated in Germany next year.

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

All material below is also available in hard form on request to Goldsmiths Research Office.

1. USA Agency for Healthcare Research & Quality (2012): [Draft Comparative Effectiveness Review](#).
2. USA health insurers – 2013 Medical Policy documents available on request from the Research Office or at [United Healthcare](#) and [Anthem Healthcare: Anthem Medical Policies](#).
3. Ontario, Canada (2011) Evidence-based review of moderate to severe acquired brain injury “to improve the quantity of ABI rehabilitation in Ontario by synthesizing the current literature into a format utilizable by front-line clinicians and laying the foundation for effective knowledge transfer to improve programs and services.” [Abiebr Executive Summary](#).
4. New Zealand - Accident Compensation Corporation [report](#) (2011).
5. BICRO registration database/emails available on request from Goldsmiths Research Office.
6. The Director of RWW can be contacted for corroboration [*contact details provided separately*].
7. QOLIBRI registration data/database available on request from Goldsmiths Research Office.
8. TOIMIA, the Finnish public health and social care network: The recommended toolkit is explained at [Tervetuloa Toumia-Toetokantaan](#); its recommendation of the QOLIBRI is shown [here](#) [*available in English from Goldsmiths Research Office*].
9. Wilde E. et al. (2010) ‘Recommendations for the Use of Common Outcome Measures in Traumatic Brain Injury Research’, *Arch Phys Med Rehabil*, 91(11), DOI 1650-1660.e17.
10. NIH clinical trials website: <http://www.clinicaltrials.gov>[*enter QOLIBRI as search term*]
11. Eli Lilly [prize for QoL research](#) (2011).
12. A partner at Leigh Day can be contacted for oral corroboration [*contact details provided separately*].

The consultant neurologist at Homerton Hospital can also be contacted to corroborate all aspects of the impact [*details provided separately*].