

Institution: Cardiff University
Unit of Assessment: UoA4
Title of case study: Cardiff research leads Welsh Government and England's Department of Health to implement systematic health check for ~250,000 adults with learning disabilities across England and Wales
<p>1. Summary of the impact (indicative maximum 100 words)</p> <p>Adults with learning disabilities (LD) often cannot adequately report illness and there is evidence that treatable illnesses go undetected. As a direct result of Cardiff University research on health checking adults in primary care, the Welsh Government and the Department of Health now provide funding for all adults with LDs across England and Wales to receive an annual health check that employs Cardiff University methods. Current data on take-up (N=78,000 per year) and evaluation of results show that nearly 250,000 adults with LDs have had new health needs identified and treatments initiated during the REF assessment period (2008-2013). Nearly 40,000 adults per year will have new health needs identified and treatments initiated as a result of the health checks, with approximately 3,500 of these being potentially serious conditions.</p>
<p>2. Underpinning research (indicative maximum 500 words)</p> <p>From 1998, a Cardiff University research team led by Professors Felce (Director, Welsh Centre for Learning Disabilities, 1989 onwards) and Kerr (Lecturer 1993, Senior Lecturer 1996, Professor 2003) has undertaken charity- and NHS-funded research that underpinned the impacts described in this case. The research did not involve academic institutions outside Cardiff University.</p> <p>Design and evaluation of health checking for adults with learning disabilities</p> <p>Adults with a learning disability (LD) are a vulnerable group with high morbidity and substantial health disparities compared to the general population. Like other citizens, the overwhelming majority live in the community and have their medical needs met in primary care. However, difficulties in understanding and communication mean that most cannot adequately recognise and report illness. There is evidence that their carers believe them to be healthier than they are and that treatable illness frequently goes undetected.</p> <p>Pro-active health checking was recognised as a potential solution to these problems and Felce and Kerr devised the Cardiff Health Check format, recruited a sample of general practices to conduct health checks for a <i>de novo</i> sample (no prior health check) of adults with LD, and evaluated their impact in terms of the identification of previously unidentified morbidity. The team then conducted a follow-up study to evaluate the impact of repeated health checks on a previously checked sample and to establish a recommended interval between checks empirically. A systematic review considers this "the most comprehensive study of repeated health checks to date"^{3.1}.</p> <p>Underpinning research findings</p> <p>The first Cardiff study^{3.2} found that new health needs were identified for 93 out of 190 participants (48%), 63% of whom had one health need newly identified, 25% two needs and 12% more than two needs. For 16 (9%) individuals, identified health needs were deemed serious, including breast cancer (1), dementia (1), asthma (1), post-menstrual bleeding (1), diabetes (2), hypothyroidism (2), high blood pressure (4) and haematuria (4). An audit of actions resulting from the health checks indicated that management had been initiated for 90% of identified needs by the time of the audit.</p> <p>The Cardiff team's second study^{3.3, 3.4} showed that identification of new health needs among a sample of 108 previously checked adults with LD who were allocated randomly to groups varying with respect to the interval between health checks (mean group intervals 28, 44 and 14 months) was similar to the <i>de novo</i> sample. The number of new needs identified was unrelated to the</p>

interval between health checks and we therefore concluded that annual health checking could be justifiable. In addition, health checking was shown to significantly increase health promotion activities over and above those involved in the checks.

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

Background publication (non-Cardiff evidencing research quality)

1. Robertson, J., Roberts, H. & Emerson, E. (2010). *Health Checks for People with Learning Disabilities: A Systematic Review of Evidence* (p. 18). Improving Health and Lives Learning Disabilities Observatory
http://www.improvinghealthandlives.org.uk/uploads/doc/vid_7646_IHAL2010-04HealthChecksSystemticReview.pdf

Key publications (Cardiff)

2. **Baxter, H.,** Lowe, K., **Houston, H.,** Jones, G., **Felce, D., & Kerr, M.** (2005). Previously unidentified morbidity in patients with intellectual disability. *British Journal of General Practice*, **56**, 93-8. <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1828252/>
3. **Felce, D., Baxter, H.,** Lowe, K., **Dunstan, F., Houston, H.,** Jones, G., **Felce, J., & Kerr, M.** (2008a). The impact of repeated health checks for adults with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, **21**, 585-596. <http://dx.doi.org/10.1111/j.1468-3148.2008.00441.x>
4. **Felce, D., Baxter, H.,** Lowe, K., **Dunstan, F., Houston, H.,** Jones, G., **Grey, J., Felce, J., & Kerr, M.** (2008b). The impact of checking the health of adults with intellectual disabilities on primary care consultation rates, health promotion and contact with specialists. *Journal of Applied Research in Intellectual Disabilities*, **21**, 597-602. <http://dx.doi.org/10.1111/j.1468-3148.2008.00432.x>

Key grants

1998-2000 Henry Smith Charity. Primary care for people with learning disabilities. £173k. Kerr, Felce.

2001-2005 Wales Office of Research and Development. The Impact of Annual Health Checks on the Health of People with Learning Disabilities and the Perceived Health of their Carers: a Longitudinal Study, £185k. Michael Kerr, David Felce, Helen Houston.

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

During the REF assessment period (2008-2013) nearly 250,000 learning disabled individuals in England and Wales have benefited from screening for physical illness that was introduced as a direct result of the Cardiff research.

Linking Cardiff underpinning research to post-2008 impact

Steps leading to policy change began prior to 2008. In 2005, the Disability Rights Commission (DRC) launched a formal enquiry into inequalities in health and health care for people with learning disabilities and mental health problems. Cardiff research evidence was fed into this enquiry and became part of its report *Equal Treatment: Closing the Gap*.^{5.1, 5.2} The DRC recommended the introduction of annual health checks for adults with learning disabilities and influenced the responsible Minister in Wales to allocate funding to entitle every adult with LD on local authority learning disability registers to an annual health check as a Directed Enhanced Service. The Cardiff Health Check was revised to become the Welsh Health Check and further work was done with Welsh Assembly Government officials to develop software so that the health check could be recorded electronically. The research was also disseminated to voluntary sector campaigning bodies, such as Mencap, who were responding to the recognised inequalities in health of this population (see Mencap 2007, *Death by Indifference*). Following initiation of annual

health checks in Wales, all individuals with diagnosed learning disability can benefit from the regular screening.

Wider adoption of the health check model

In September 2008, the NHS and British Medical Association announced plans for a Directed Enhanced Service to deliver annual funded health checks for adults with LD across England. Key evidence, such as from Mencap, used Cardiff research to support recommendations by an independent inquiry into access to healthcare for people with learning disabilities.^{5.3} As in Wales, the health checks format followed Cardiff methods, now known as the Welsh Health Check.

Impact of health checks across England and Wales

In Wales, the implementation of health checks has been monitored by the National Public Health Service (now Public Health Wales).^{5.4} A series of reports have shown increased take-up. In 2008-2009, 4,693 Welsh adults with LD received health checks, with positive focus group feedback.

"Health checks will generate increased referrals and ... [] ... in the long term, cost benefits are likely through improving quality of life, improving mental and physical health, and therefore supporting people to lead more independent and fulfilling lives." *Phil Boulter, Consultant Nurse at Surrey and Borders Partnership NHS Foundation Trust, in Eyes on Evidence (March 2012), NHS Evidence/ National Institute for Health and Clinical Excellence.*^{5.5}

In England, the implementation of health checks is being monitored by the Improving Health and Lives Learning Disabilities Observatory.^{5.6} Their latest report showed that 72,782 adults with LD in England received a health check in 2010-2011.

Extrapolating from Cardiff research, the combined England and Wales extent means that 78,000 adults are screened annually and nearly 40,000 adults per year will have new health needs identified and treatments initiated, of whom possibly 3,500 will have had potentially serious conditions identified. Over the REF assessment period that amounts to approximately 250,000 adults with LD having new health needs identified as a result of the Cardiff research.

International uptake of Cardiff model

Wales was the first country in the world to introduce comprehensive annual health checking for adults with LD, followed by Australia and England. In addition, there has been considerable usage of the Cardiff Health Check format in New Zealand. Overall, there has been sustained, widespread behaviour change among General Practitioners (GPs) who now have regular contact with people with LD when performing health checks.

"Targeted health checks should be considered to constitute an effective and important adjustment to the operation of primary health care services in the UK as required by the Disability Discrimination Acts 1995 and 2005 and the Equality Act 2010."^{5.7}

Cost benefits of health checks

The one study that has included a comprehensive assessment of the cost of health checks concluded that the health care check was relatively cheap and affordable compared to standard care, and was not associated with higher health costs for service usage.^{5.8} Mean care costs for adults who received standard care only was greater than for the adults who received the health-check intervention. The higher costs were due to differences in unpaid carer support costs.

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

1. Cardiff research informed the report *Equal Treatment: Closing the Gap*; a formal investigation into physical health inequalities experienced by people with learning disabilities and/or mental health problems, The Disability Rights Commission (2006). Pages 18, 48, 65,110. <http://disability-studies.leeds.ac.uk/files/library/DRC-Health-FI-main.pdf> [pdf downloaded from website on 26 July 2013 available from HEI]

2. Cardiff research informed the report *Equal Treatment: One Year On*; report of the Reconvened Formal Inquiry Panel of the DRC's Formal Investigation, The Disability Rights Commission (2007). Pages 6, 19. <http://disability-studies.leeds.ac.uk/files/library/DRC-closing-the-gap-fi.pdf> [pdf downloaded from website on 26 July 2013 available from HEI]
3. Cardiff research informed the report by Michael, J. (2008). *Healthcare for All: Report of the Independent Inquiry into Access to Healthcare for People with Learning Disabilities*. (References to health checks on pp. 16, 40, 42, 47) [available from HEI on request] http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_106126.pdf
4. Evidence of use of (Cardiff) Health Checks in Wales can be found in the evaluation of annual health checks of adults with a learning disability, Public Health Wales, commencing with *Monitoring the public health impact of health checks for adults with a learning disability in Wales 1st report, Jan 2008*. [http://www2.nphs.wales.nhs.uk:8080/vulnerableadultsdocs.nsf/\(\\$all\)/2a48ec98b50568c280257404004e9c5a/\\$file/monitoring_the_public_health_impact_of_health_checks_for_adults_with_a_learning_disability_in_wales_v7_d080208.doc](http://www2.nphs.wales.nhs.uk:8080/vulnerableadultsdocs.nsf/($all)/2a48ec98b50568c280257404004e9c5a/$file/monitoring_the_public_health_impact_of_health_checks_for_adults_with_a_learning_disability_in_wales_v7_d080208.doc) [pdf downloaded from website on 29 July 2013 available from HEI]
5. Evidence for the perceived benefit of the (Cardiff) Health Checks can be found in *Eyes on Evidence*, monthly publication of NHS Evidence. March 2012 issue contains an article on Health checks for people with learning disabilities. The quote from the Consultant Nurse comes from that article. <https://www.evidence.nhs.uk/documents/eyes-on-evidence-antibiotic-prescribing-bicycle-schemes-health-checks.pdf> [pdf downloaded from website on 29 July 2013 available from HEI]
6. Evidence of use of (Cardiff) Health Checks in England can be found in the monitoring reports on health checking in England can be obtained from Improving Health and Lives Learning Disabilities Observatory at (see p. 3, para. 14) http://www.improvinghealthandlives.org.uk/uploads/doc/vid_11882_IHAL2011-08%20Health%20Checks%20for%20People%20with%20Learning%20Disabilities%202008-9%20%202010-11.pdf [pdf downloaded from website on 26 July 2013 available from HEI]
7. Evidence for the perceived benefit by GPs of (Cardiff) Health Checks can be found in *A Step by Step Guide for GP Practices: Annual Health Checks for People with a Learning Disability*. Dr Matt Houghton and the RCGP Learning Disabilities Group (2010). http://www.rcgp.org.uk/clinical-and-research/clinical-resources/~/_media/Files/CIRC/CIRC-76-80/CIRCA%20StepbyStepGuideforPracticesOctober%2010.ashx (Reference to Cardiff health check methods on p.4; pdf downloaded from website on 21 October 2013 available from HEI)
8. Evidence for service cost benefits of (Cardiff) Health Checks can be found in Romeo R., Knapp M., Morrison J., Melville, C., Allan, L., Finlayson J., & Cooper, S.A. (2009). Cost estimation of a health-check intervention for adults with intellectual disabilities in the UK. *Journal of Intellectual Disability Research*, 53, 426-439. <http://dx.doi.org/10.1111/j.1365-2788.2009.01159.x> [available from HEI on request]

Referees

9. The Chief Executive of Mencap will verify the impact our work has had on identification of physical ill-health amongst those with learning disability.
10. The Clinical Director of IDEA Services, Christchurch, New Zealand will verify the impact of our work on policy and services in New Zealand.