

Institution: University of Glasgow (UofG)		
Unit of Assessment: UoA 4 (Psychology, Psychiatry and Neuroscience)		
Title of case study: Improving the health of adults with learning disabilities in Scotland and England		
Period when the underpinning research was undertaken: 2002–present		
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:
(1) Prof Sally-Ann Cooper;	(1) Chair of Learning Disabilities;	(1) 1999–2019; 2019–present;
(2) Prof Andrew Jahoda;	Honorary Senior Research Fellow;	(2) 2007–present;
(3) Prof Jill Morrison;	(2) Professor of Learning Disabilities;	(3) 1990–present;
(4) Prof Craig Melville;	(3) Professor of General Practice;	(4) 2004–present;
(5) Ms Eleanor Grieve;	(4) Professor of Intellectual	(5) 2010–present;
(6) Dr Sara MacDonald;	Disabilities Psychiatry;	(6) 2002–present;
(7) Prof Alex McConnachie;	(5) Research Associate;	(7) 1996–present;
(8) Ms Nicola Greenlaw.	(6) Senior Lecturer;	(8) 2010–present.
	(7) Professor of Clinical Trials	
	Biostatistics;	
	(8) Consultant Biostatistician.	
Period when the claimed impact occurred: 2014–present		
Is this case study continued from a case study submitted in 2014? No		
1. Summary of the impact		
<p>Adults with learning disabilities have multi-morbidity yet experience barriers accessing healthcare. UofG researchers developed, trialled and implemented two interventions that address this issue. First, annual health checks delivered in primary care improve health and provide substantial cost savings. They are recommended in four UK clinical guidelines and quality standards (2015–2019), and included in Scotland’s strategies for learning disabilities (2015–2021) and mental health (2017–2027). Second, online training has enabled primary care staff in Scotland and England to deliver tailored psychological therapies for depression. One of these therapies was repurposed to support emotional wellbeing of people unable to access routine services during the coronavirus pandemic.</p>		
2. Underpinning research		
<p>There are approximately 261,000 adults with learning disabilities in Scotland and England (plus their families, carers and care providers). They have a different pattern of, and more, health needs compared with other people, and NHS services often are ill equipped to address their most prevalent problems. This leads to substantially poorer health, and premature deaths 20–25 years earlier than the general population; 40% of these premature deaths would have been amenable to care. UofG researchers are committed to developing, trialling and implementing interventions to improve the health (and health care) of adults with learning disabilities.</p>		
Health checks		
<p>In 2002, NHS Health Scotland appointed Prof Sally-Ann Cooper to chair the Scottish Health Needs Assessment Report for people with learning disabilities. Its 2004 report recommended research on health checks. The first controlled trial of health checks in NHS primary care for adults with learning disabilities demonstrated 1-year outcomes of increased detection of new health needs; improved management of long-term conditions; and more health promotion, compared to the standard care group (Cooper, Morrison, Melville; 2006) [3.1]. A health economic evaluation conducted in collaboration with Prof Martin Knapp (London School of Economics) found that health checks were inexpensive, with the mean care cost higher for the standard care-only control group (Morrison, Melville, Cooper; 2009) [3.2].</p>		
<p>In 2007, Cooper and Dr Nadine Harrison (primary care advisor) co-chaired a clinical group commissioned by the Scottish Government Primary Care Directorate and comprising all 14 Scottish Health Boards. This group identified minimum components of a health-check intervention for adults with learning disabilities for use nationally. Working with NHS Greater Glasgow and Clyde (GG&C) Health Board, Cooper subsequently developed and piloted a health check for adults with learning disabilities that was led by practice nurses (June–December 2011). NHS GG&C also supported recruitment into a UofG cluster randomised</p>		

controlled trial (RCT) of the health check, which was conducted at 38 Scottish general practices during 2011–2013 (**Cooper, Morrison, McConnachie, Melville, Greenlaw, Grieve**) [3.3]. The health check showed clinical and cost effectiveness at the 9-month outcomes evaluation when compared with standard care [3.3]. This RCT is the only one conducted in the UK healthcare system to date.

Psychological therapies to manage depression

Depression is common among adults with learning disabilities. Nonetheless, National Institute for Health and Care Excellence (NICE) guidance on mental health problems in this population has highlighted that specialist and mainstream services often fail to deliver appropriately adapted psychological therapies.

A key barrier is that people with learning disabilities might lack the necessary communicative and cognitive abilities to engage in talking therapies such as cognitive behavioural therapy. **Prof Andrew Jahoda** and colleagues adapted behavioural activation as a psychological therapy for use in this group. Behavioural activation has proven efficacy in the general population, and focuses on helping people to re-engage with purposeful activity and break out of a negative cycle of low mood and withdrawal. During 2011–2012, a feasibility study of the intervention (BeatIt) was conducted among 23 people with learning disabilities (**Jahoda, Melville, Cooper**) [3.4]. The unique feature of BeatIt is that service users work with a therapist while being supported by an important person in their life (e.g. family member or carer). Changes from baseline were reported for depressive symptoms immediately after the intervention (3 months) and at follow-up (6 months).

The feasibility study [3.4] was followed by a multicentre RCT of BeatIt (**Jahoda, Cooper, McConnachie, Melville**) [3.5]. This study was led by **Jahoda** and funded by the UK National Institute for Health Research (2013–2017). It compared BeatIt with a guided self-help intervention using a psychoeducational approach (StepUp), designed by **Melville**. StepUp was chosen for the RCT as the funder required an active comparison rather than treatment as usual, and it has a different set of active components than BeatIt. The RCT was the first large-scale study of a psychological intervention for depression among people with learning disabilities. In addition, with 141 participants and 12 months' follow-up, it was the largest RCT of any individual psychological therapy completed for this population. The RCT also demonstrated that a range of staff working in specialist clinical services for people with learning disabilities could be trained to provide BeatIt and StepUp [3.5]. Both interventions were delivered without harm; with excellent fidelity; and were associated with statistically significant reductions from baseline in self-reported depression scores after therapy, which were maintained at follow-up. Qualitative data showed that therapists, service users and supporters were positive about the therapy process and its impact [3.5]

3. References to the research

1. **Cooper S-A, Morrison J, Melville C**, Finlayson J, Allan L, Martin G, Robinson N (2006) Improving the health of people with intellectual disabilities: outcomes of a health screening programme after 1 year. *J Intellect Disabil Res*;50(9):667–677 (doi:[10.1111/j.1365-2788.2006.00824.x](https://doi.org/10.1111/j.1365-2788.2006.00824.x)). [Available on request from HEI]
2. Romeo R, Knapp M, **Morrison J, Melville C**, Allan L, Finlayson J, **Cooper S-A** (2009) Cost-estimation of a health check intervention for people with intellectual disabilities in the UK. *J Intellect Disabil Res*;53(5):426–439 (doi:[10.1111/j.1365-2788.2009.01159.x](https://doi.org/10.1111/j.1365-2788.2009.01159.x)). [Available on request from HEI]
3. **Cooper S-A, Morrison J**, Allan L, **McConnachie A, Melville C**, Baltzer M, McArthur L, Lammie C, **Greenlaw N, Grieves E**, Fenwick E (2014) [Practice nurse health checks for adults with intellectual disabilities: a cluster design randomised controlled trial](https://doi.org/10.1016/S2215-0366(14)00078-9). *Lancet Psychiatry*;1(7):511–521 (doi:[10.1016/S2215-0366\(14\)00078-9](https://doi.org/10.1016/S2215-0366(14)00078-9)).
4. **Jahoda A, Melville CA**, Pert C, **Cooper S-A**, Lyn H, Williams C, Davidson C (2015) [A feasibility study of behavioural activation for depressive symptoms in adults with intellectual disabilities](https://doi.org/10.1111/jir.12175). *J Intellect Disabil Res*;59(11):1010–1021 (doi:[10.1111/jir.12175](https://doi.org/10.1111/jir.12175)).
5. **Jahoda A**, Hastings R, Hatton C, **Cooper S-A**, Dagnan D, Zhang R, **McConnachie A**, [...], **Melville C** (2017) Comparison of behavioural activation with guided self-help for treatment

of depression in adults with intellectual disabilities: a randomised controlled trial. *Lancet Psychiatry*;4(12):909–919 ([doi:10.1016/S2215-0366\(17\)30426-1](https://doi.org/10.1016/S2215-0366(17)30426-1)).

Grants

- **Cooper S-A** (2002–2004) The one year outcomes of a health check programme for people with learning disabilities. Greater Glasgow Primary Care NHS Trust R&D. GBP41,427.
- **Cooper S-A** (2011–2013) Practice nurse led health checks for adults with learning disabilities. Cluster randomised controlled trial. Scottish Government. GBP235,000.
- **Jahoda A** (2013–2017) BEAT-IT: A randomised controlled trial comparing a behavioural activation treatment for depression in adults with learning disabilities with an attention control. National Institute for Health Research ([HTA10/104/34](https://doi.org/10.1016/S2215-0366(17)30426-1)). GBP1,207,488.

4. Details of the impact

UofG researchers have addressed health inequalities among adults with learning disabilities in Scotland and England through their work on health checks [3.1–3.3] (**impact 1**), and psychological therapies to manage depression [3.4–3.5] (**impact 2**).

Impact 1. Health checks

UofG research provided the evidence base for two NICE clinical guidelines. NG11 (May 2015) on challenging behaviour and learning disabilities [5.A] recommends that general practices *should* (i.e. must be done, rather than just considered) offer an annual physical health check to people with learning disabilities [3.1, 3.2]. NG54 (September 2016) was chaired by **Cooper** and addresses mental health problems among people with learning disabilities [5.A]. This guideline recommends using a standardised template for annual physical health checks [3.1–3.3]. Quality standards are linked to NICE clinical guidelines as a way for general practices and clinical commissioning groups to prioritise and plan improved quality healthcare. For QS101 (linked to NG11; published October 2015, updated July 2019), the second of 12 quality statements was that people with learning disabilities undergo a comprehensive annual health check at their general practice [5.B]. The first of five quality statements for QS142 (linked to NG54; January 2017) was that young people and adults with a learning disability have an annual health check that includes a review of mental health problems [5.B].

The Scottish Government's [Keys to Life](#) strategy aims to help people with learning disabilities to live longer, healthier lives. This policy was developed by the Health and Social Care Integration Directorate and took evidence from **Cooper's** research [3.1–3.3]. Strategic Outcome 1 ('A healthy life') of the *Keys to Life* 2015–2017 Implementation Framework and Priorities invested in the creation of the Scottish Learning Disabilities Observatory (SLDO) at UofG [5.C], with an initial GBP1,200,000 in funding to **Cooper**, which has been extended thrice since 2015. SLDO conducts research to generate meaningful intelligence to inform policy and practice, and has highlighted the role of annual health checks. *Keys to Life* 2019–2021 [5.C] includes an implementation group dedicated to supporting annual health checks in primary care nationwide, applying the tools developed by **Cooper** and colleagues, and an electronic template used by NHS GG&C. The importance of UofG research [3.1–3.3] for *Keys for Life* is highlighted by the former Strategic Clinical Lead/Professional Advisor for learning disabilities policy: "*I and my colleagues drew considerably on Prof Cooper's findings. In particular, her research on health checks... directly influenced the inclusion of a Scotland-wide implementation ... for people with learning disabilities into policy*" [5.C]. The Chair of the Learning Disabilities Health Check Implementation Group confirms that health checks were being delivered in all Scottish health boards by 2020 [5.C]; however, all screening activity was suspended from March 2020 owing to the coronavirus pandemic.

In 2016, **Cooper** presented evidence on health checks to the Scottish Government's Principal Medical Officer for mental health and the mental health policy team. The Principal Medical Officer highlighted that "*Prof Cooper's research on health checks for people with learning disabilities has had a direct impact on Scottish Government policy*" [5.D]. Scotland's Mental Health Strategy 2017–2027 (published March 2017) committed to delivering a quality indicator profile for mental health services [5.D]. One of the five quality outcomes indicators for equitable NHS care is the percentage of people with learning disabilities who have received a health

check within the previous 12 months (September 2018) [5.D]. Inclusion of this indicator was informed by UofG research [3.3].

During 2002–2014, **Cooper** worked with NHS GG&C staff to pilot, test and refine health-check interventions. A 2018 qualitative study on the perceptions of practice nurses who delivered health checks found their initial misgivings about this intervention to be unsubstantiated; health checks were considered easy to implement, with universal support for their continuation [5.E]. **Cooper** has also engaged with all Scottish health boards to promote uptake.

The health check is clinically effective across multiple types of conditions, in particular for detecting new health need and managing long-term conditions. Qualitative feedback from carers of people with learning disabilities included: *“I was really happy because I feel that people like her don’t get enough attention, like personally her teeth, she has not had them seen since she left school and she is 24 now”*; *“I was quite happy because she [...the nurse..] was just checking everything she should have been getting”*; *“I think deep down you done everything, her feet, everything she needed done”*; *“It was very informative and very good”* [5.F]. An economic analysis conducted by **Grieve** [5.F] demonstrated that practice nurse-led health checks [3.3] were both cost-effective and cost saving, with a net monetary benefit of GBP651 per person for NHS Scotland; this could equate to a population net monetary benefit of GBP13,745,865 in Scotland, where the 2011 census data indicates potential reach of 21,115 adults with learning disabilities. The data suggest 60% population coverage for health checks (much higher than the 23% for cervical screening and 39% for bowel screening achieved among people with learning disabilities), achieving a net monetary benefit of GBP8,247,519. This value could rise if the *Keys to Life* implementation group strategy [5.C] proves successful.

Impact 2. Psychological therapies to manage depression

UofG researchers showed that community nurses and allied healthcare staff can be trained to provide BeatIt and StepUp on an outreach basis, thereby avoiding referral to specialist therapists [3.5]. A 2017 presentation by NHS Education for Scotland (NES) highlighted a need for competence-based, accredited training of staff [5.G]. **Jahoda** and colleagues had identified online training as an accessible and viable route for delivering BeatIt and StepUp to people with learning disabilities and depression. Consequently, they developed e-learning materials for use in both Scotland and England, with NHS England providing a GBP10,000 grant to produce video content. These online resources—provided to healthcare professionals for free by NES and Health Education England (HEE)—went live in June 2019 [5.G]. Approximately 780 individuals have completed the online training, with over 80 NHS Scotland staff members receiving face-to-face training after the BeatIt RCT [3.5] ended in 2018 [5.G]. Training is also being given to the Increasing Access to Psychological Therapies services in Cumbria and Sunderland [5.G]. The e-learning materials have been accessed by users in the USA, Canada and Australia [5.G]. Pathways have been established to deliver BeatIt and StepUp to people with learning disabilities by four Scottish health boards (GG&C; Ayrshire and Arran; Grampian; Lanarkshire), and by some services in England (e.g. services in Lancashire, and the Cumbria, Northumberland and Tyne and Wear NHS Foundation Trust). In 2020, a USD47,000 trial was initiated to examine the feasibility of delivering BeatIt in the USA through the national [START](#) network for people with learning disabilities.

Post-intervention interviews highlight a positive response to BeatIt and StepUp among service users, their supporters and therapists [5.H]. For example: *“Since I’ve been to therapy it’s totally different because I’ve started cleaning up my flat, cleaning myself up and going shopping. I have come on leaps and bounds and it’s all because of this”* (service user); *“He’s totally different. His confidence has really improved now. It makes me happy and I can relax now knowing that he’s got friends. He never had friends before”* (supporter); *“I really liked the resource, the way it was set up with your steps, what to do in the booklets, just the amount of conversation that that generates”* (therapist) [5.H]. The delivery costs of these interventions were approximately 4.0%–6.5% of service users’ total support costs, representing only a small additional financial outlay in relation to existing care costs [5.H].

The StepUp e-learning materials have been reviewed and revised to ensure that they continue to meet the needs of service users. As part of the UofG response to COVID-19, they were repurposed for outreach use to support the emotional wellbeing of people with learning disabilities, who were unable to access routine services during lockdown. Resource development was led by UofG, in collaboration with the Scottish Commission for Learning Disabilities (SCLD), and with assistance from the Universities of Lancaster and Warwick [5.I]. In April 2020, six online booklets—covering issues such as anxiety, feeling down and poor sleep—were made freely available for download on the SCLD website [5.I]. As digital access may not be appropriate for many people with learning disabilities, UofG and SCLD obtained a grant of GBP13,312 from the Scottish Government’s Wellbeing fund to make hard copies available for delivery by health and social care organisations, and people’s families. To further increase accessibility, Dutch and Welsh translations are also available. By December 2020, there had been over 5200 downloads, with 12,555 printed copies distributed across Scotland [5.I]. Feedback received by SCLD demonstrated that people with learning disabilities appreciated having physical booklets to work with, as they provided a tangible connection with service providers at a time when face-to-face contact was limited [5.I]. The value of the resources was highlighted in a Motion to the Scottish Parliament on 23 April 2020 [5.I].

Adapted versions of the booklets were made available by Canada’s largest mental health teaching hospital (CAMH) [5.I]. By December 2020, a total of 461,000 unique visits had been recorded by two webpages hosting these resources. Hard copies of the booklets are being used in a virtual course that CAMH runs to help people with learning disabilities cope during the pandemic [5.I]. A CAMH representative stated: “*The booklets help people take actionable steps to address these challenges. Not only are the situations relatable and the language appropriate, but each booklet includes specific concrete tasks to be discussed and completed. Dr. Jahoda’s team has been able to act quickly and responsively to a terrible situation, using their evidence from their prior research and input from community partners*” [5.I].

5. Sources to corroborate the impact (PDFs uploaded for all listed items)

- A. NICE clinical guidelines: (1) [NG11](#) (May 2015). See Recommendation 9.4.2. (p.196), supported by UofG studies 3.1 and 3.2 (p.28, p.192, p.287, p.288, p.335, p.361). (2) [NG54](#) (September 2016). See Recommendation 7.5.1 (p.234), supported by UofG studies 3.1–3.3 (p.10, p.211, p.214, p.215, p.352, p.375, Table 82).
- B. NICE quality standards: (1) [QS101](#) (October 2015). See Quality Statement 2 in the July 2019 update (p.11–p.14); (2) [QS142](#) (January 2017). See Quality Statement 1 (p.5–p.8).
- C. Scottish Government *Keys to Life*: (1) 2015–2017 Implementation Framework and Priorities. See Strategic Outcome 1 (p.8–p.9) for [SLDO](#); (2) [2019–2021](#) Implementation Framework and Priorities. See p.17, p.32; (3) Testimonial from the former Strategic Clinical Lead/Professional Advisor, Learning Disabilities Policy; (4) Testimonial from the Chair, Learning Disabilities Health Check Implementation Group.
- D. Scottish Government mental health policy: (1) Testimonial from the Principal Medical Officer, Mental Health Directorate; (2) [Mental health strategy 2017–2027](#). See Action 38 (p.6, p.37); (3) [Mental health quality indicators](#) (September 2018). See Eq3 LD health checks (p.26).
- E. Perceptions of practice nurses on health checks: [J Intellect Disabil Res 2018; 62:349–357](#).
- F. Benefits of health checks: (1) Transcripts of verbatim qualitative interviews with carers available on request from UofG; (2) Economic analysis of health checks.
- G. BeatIt and StepUp e-learning modules: (1) NES presentation outlining a need for training (2017). See slide 57; (2) NES [landing page](#); (3) HEE [landing page](#). NB: User data were gathered from the NES and HEE e-learning sites.
- H. User experiences and costs of BeatIt and StepUp: (1) [Health Technol Assess 2018;22\(53\)](#). See Chapters 6–8; (2) [J Appl Res Intellect Disabil 2019; 32:819–830](#); (3) [J Appl Res Intellect Disabil 2019; 32:323–335](#).
- I. COVID-19 resources: (1) SCLD [landing page](#); (2) Copies of the booklets, with user guides; (3) Testimonial from the Head of Delivery, SCLD; (4) Motion [S5M-21545](#) to the Scottish Parliament (April 2020); (5) [CAMH](#) and [H-CAARD](#) landing pages; (6) Testimonial from the Director of the H-CARRD programme, CAMH.