

Institution: Queen Margaret University, Edinburgh		
Unit of Assessment: UoA 4 Psychology, Psychiatry and Neuroscience		
Title of case study: Reducing waiting times for Autism diagnosis in Scotland		
Period when the underpinning research was undertaken: 2011-2014		
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:
Professor Kirsty Forsyth	Professor	2000-date
Dr Marion Rutherford	Research Fellow	2011-date
Dr Karen Mackenzie	Honorary OT Professor	2015-date
Dr Aja Murray	Research Fellow	2013-2020
Tess Johnston	Research Administrator	2011-2013
Ciara Catchpole	Snr Research Administrator	2011-2013
Deborah McCartney	Research Administrator	2013-2017
Period when the claimed impact occurred: December 2014-2020		
Is this case study continued from a case study submitted in 2014? N		
1. Summary of the impact <p>In Scotland, autism is estimated to affect 103.50/10,000 people. Lengthy waiting times for diagnosis is a significant problem affecting 74% of children and 59% of adults referred. Females particularly experience issues from lengthy waiting times, including missed or delayed diagnosis. Cutting edge QMU research is directly responsible for reducing the burden of Scottish diagnostic waitlists for autism. QMU researchers analyzed the nature of waiting times and ways these could be reduced with reference to the Scottish Intercollegiate Guidelines Network (SIGN) and National Institute for Health and Care Excellence (NICE) autism guidelines. QMU research informed key Scottish Government decision making and major restructuring of NHS provision nationally. Based on QMU research, Scottish Government funded national implementation (including 71% of health boards, representing 92% of the population) has supported new practices to reduce waiting times (leading to up to 52 week reductions in waits). Other impacts include identifying more females through improved male/female diagnosis ratio, increased use of autism diagnostic tools by practitioners, increase in knowledge and awareness amongst staff and creation of new senior practitioner posts.</p>		
2. Underpinning research <p>Prior to the QMU research, there was no evidence about the nature of the problem or possible solutions to long waits for diagnosis for people with presumptive autism in Scotland. There was no robust evidence about waiting times or empirical data on services undertaking diagnosis. Pioneering QMU research on autism diagnosis waiting times was completed 2011-2014 as part of an influential multidisciplinary collaboration led by QMU (PI Forsyth) with Scottish Government endorsement inclusive of funding from Minister for Public Health & Sport, & Minister for Mental Health alongside research results feeding directly to policy makers.</p> <ul style="list-style-type: none"> • Forsyth (PI) [£234,111] Autism Achieve Alliance: Understanding waiting times in adult and children services who diagnose Autism Spectrum Disorders. Office of the Minister for Public Health and Sport. Scottish Government. • Forsyth (PI) [£250,000] Autism Achieve Alliance: How can waiting times be reduced in adult services who diagnose Autism Spectrum Disorders. Office of the Minister for Public Health and Sport. Scottish Government. 		

- **Forsyth (PI) [£700,737]** Autism Achieve Alliance: National Autism Implementation Team (NAIT). Funding to facilitate use of QMU protocols, policies and procedures nationally. Office of the Minister for Mental Health, Scottish Government.

Key Research 2011-2014

1. QMU research measured adherence to SIGN and NICE clinical guidelines and whether adherence influenced waiting times for diagnosis in Scotland [R3.1; R3.2].
2. Studies systematically investigated the extent and cause of waiting times for diagnosis in children and adults [R3.3; R3.4]. This research provided the first evidence of lengthy waiting times for diagnostic assessment in Scotland (331 days for children and 162 days for adults). On conclusion, it was found that 79% of child cases and 59% of adult cases breached the 119-day UK standard for waiting times for diagnosis [R3.3; R3.4].
3. QMU research showed for the first time the scale of waiting times and associated under-diagnosis of females, showing there was an urgent need to address this issue from both a gender equality and economic perspective, considering the high personal and economic costs of undiagnosed autism [R3.5].
4. An important investigation was made by QMU into average age of diagnosis in adults (identified as 31 years) [R3.5]. Given that adults with autism cost health and social care services more than those with dementia, cancer or heart disease, this late diagnosis is a significant issue for Government and Society
5. There is debate within this field about which standardized diagnostic instruments to use within the diagnostic assessment process. We identified strengths and weaknesses in current diagnostic practice, together with guidance for practitioners to aid effective decision making and training [R3.6].
6. Several key recommendations were made as a result of the research, representing vital messages for policymakers and practitioners, including real-world advice on guideline adherence [R3.2; R3.2], that comprehensive information about the individual that is directly relevant to the diagnosis of autism should be routinely sought prior to, or at the point of referral [R3.3], the necessity to develop and maintain multi-agency diagnostic pathways and collaborative local action plans [R3.4], the need to take action to rectify the under recognition of females with autism [R3.5], and the need for wider training in use of standardised interview (clinical history) tools and clinical observation tools [R3.6].

3. References to the research

The research underpinning this impact has been published in leading autism journals with strong impact factors and has been supported by competitively awarded grants. [QMU researchers bolded]

R3.1 **McKenzie, K., Forsyth, K., O'Hare, A., McClure, I., Rutherford, M., Murray, A., & Irvine, L.** (2016). The relationship between waiting times and 'adherence' to the Scottish Intercollegiate Guidelines Network 98 guideline in autism spectrum disorder diagnostic services in Scotland. *Autism*, 20(4), 395-401. <https://doi.org/10.1177/1362361315586136>

R3.2 **McKenzie, K., Rutherford, M., Forsyth, K., O'Hare, A., McClure, I., Murray, A. L., & Irvine, L.** (2016). The relation between practice that is consistent with NICE guideline 142 recommendations and waiting times within Autism Spectrum Disorder diagnostic services. *Research in Autism Spectrum Disorders*, 26, 10-15. <https://doi.org/10.1016/j.rasd.2016.03.002>

R3.3 **McKenzie, K., Forsyth, K., O'Hare, A., McClure, I., Rutherford, M., Murray, A., & Irvine, L.** (2015). Factors influencing waiting times for diagnosis of Autism Spectrum Disorder in children and adults. *Research in developmental disabilities*, 45, 300-306. <https://doi.org/10.1016/j.ridd.2015.07.033>

R3.4 **Rutherford, M., McKenzie, K., Forsyth, K., McCartney, D., O'Hare, A., McClure, I., & Irvine, L.** (2016). Why are they waiting? Exploring professional perspectives and developing solutions to delayed diagnosis of autism spectrum disorder in adults and children. *Research in Autism Spectrum Disorders*, 31, 53-65. <https://doi.org/10.1016/j.rasd.2016.06.004>

R3.5 **Rutherford, M., McKenzie, K., Johnson, T., Catchpole, C., O'Hare, A., McClure, I., Forsyth, K., McCartney, D & Murray, A.** (2016). Gender ratio in a clinical population sample, age of diagnosis and duration of assessment in children and adults with autism spectrum disorder. *Autism*, 20(5), 628-634. <https://doi.org/10.1177/1362361315617879>

R3.6 **Rutherford, M., McKenzie, K., McClure, I., Forsyth, K., O'Hare, A., McCartney, D., & Finlayson, I.** (2016). A national study to investigate the clinical use of standardised instruments in autism spectrum disorder assessment of children and adults in Scotland. *Research in Autism Spectrum Disorders*, 29, 93-100. <https://doi.org/10.1016/j.rasd.2016.05.003>

4. Details of the impact

Context: In Scotland, autism is estimated to affect 56,449 individuals, and there are around 8,000 new cases yearly. Lengthy waiting times and delayed diagnosis exacerbates costs, and creates dissatisfaction and stress. Waiting times is a chronic problem, and prior to the QMU research, there was no evidence about how to reduce the waiting time burden. QMU research led to significant new approaches to reducing waiting times. QMU's research has had profound implications for the organisation and delivery of autism services, has provided evidential support for Scottish Government policy decisions, and has been highly influential across NHS Scotland.

Pathways to impact: QMU research has been persuasive and inspired significant national action over standards and pathways for waiting times and autism diagnosis in Scotland. Research has been disseminated through Scottish Government websites [S1] [S2] referenced in influential international and national autism diagnostic standards (SIGN ASD guidelines, Australian ASD guidelines) [S3] and was recently made available on a specifically designed website to support ongoing ease of access and a single point of national reference. Since the site went live, there has been additional international reach, with 17,238 hits from 49 countries recorded in the 8 months since inception. Because waiting times are a high profile target and a key barometer for performance of services, pathways and diagnostic protocols developed as a result of the QMU research are recognised and supported by the Scottish Government [S2]. QMU's autism research received Governmental and ministerial endorsements [S4] [S2] and there was additional stimulus provided by Ministerial appointment of a National Improvement Advisor 2015-2018 to implement QMU research findings across Scotland [S2]. This multifaceted dissemination, take-up, and active Government support has led to enduring and sustainable impacts across the NHS for clinicians, service users and their families.

Beneficiaries, Reach and Significance: Beneficiaries are the NHS, practitioners and people with autism and their families. Major impacts associated with the use of QMU's autism research are: significant reduction in waiting times for autistic people, increase in recognition of females with autism, increased use of autism diagnostic tools by practitioners, creation of a national practice community, and creation of new senior practitioner posts.

Reducing waiting times: Application of QMU research has used to develop evidence based pathways and new multidisciplinary working practices [S5.1] [S5.2] [S6] [S7] [S8]. Large clinical services across urban and remote and rural areas of Scotland have established new systems for providing, recording and monitoring autism diagnosis [S5.1] [S5.2] [S6] [S7] [S8]. This has led to significant reductions in duration of waitlists in Scotland [S5.1] [S5.2] [S6] [S8]. More efficient services have been demonstrated and evidenced by Government funded evaluations. In 2014, national evaluation of a model for autism diagnosis directly derived from QMU autism research (71% of Scottish Health Boards representing 92% of the population and 50 diagnosticians) demonstrated a statistically significant reduction in the wait for diagnosis (average waits reduced from 147 days to 119 days - longest reduction was 364 days) [S5.1]. Following this, an NHS organization with 21 hospitals completely reorganised their autism diagnosis services drawing on the research and an evaluation demonstrated a statistically significant reduction in waits (reduction in NHS waiting times from 270 days to 122.5 days) [S5.2].

Reduced waits and recognition for females with autism: QMU autism research has raised clinicians' awareness of problematic waiting times and associated under-recognition of females with autism. New diagnostic services, developed using QMU research, have led to an increased awareness of the presentation of females with autism and the risk of late diagnosis, leading to improved recognition, support and reductions in waits [S8]. A large urban NHS organization (serving a population of 897,770) improved their male/female diagnosis ratio from 5:1 to 2.7:1 across 400 cases [S5.2] following an improvement process drawing on QMU research.

Increased use of Autism diagnostic instruments in the assessment pathway: QMU research has supported service planning associated with waiting times and diagnosis by influencing autism diagnostic instruments used in practice [S2] [S7]. Uptake of recommendations derived from QMU autism research led to an increase in the number of practitioners trained in and using autism diagnosis instruments leading to more efficient and effective pathways nationally [S2] [S7]. Diagnosticians (representing NHS Boards serving a population of 3,436,105 and 35,564 autistic people) were trained in 2013 in ADOS autism diagnostic instruments [S2] [S7]. This 2013 training led to impacts 2014 onwards by increasing capacity of expert staff to identify people with autism [S2] [S7].

Creation of practice community to reduce waiting times and improve diagnosis: In 2014, QMU's innovative approach to autism waiting times and diagnosis led to the development of a national autism diagnostic community of practice supporting the direct translation of the research into clinical practice. An Autism Knowledge Hub was established in 2018 due to practitioner request, with Government funding, to facilitate use of QMU research findings with national and international active members [S2]. A protocol was created developing a new single pathway for diagnosis. For the first time, in 2016, services collaborated to develop single pathways to reduce waiting times and matching of professional skills to need [S5.1]. Health board areas have since been revising and updating pathways based development work, using QMU evidence to write localised and bespoke pathways [S2] [S6] [S7] [S8].

Creation of new national senior practitioner posts: A key recommendation arising from QMU's autism research was to ensure maintenance of improvements in multi-agency diagnostic pathways and collaborative local action plans. The Scottish Government "Programme for Government 2019-2020" [S9] committed funding to support these recommendations. This funding was released to facilitate use of QMU protocols, policies and procedures nationally [S2]. Three full time senior practitioner posts were recruited with the objective of working to maintain improvements generated from the QMU research in autism diagnosis [S2].

Reach beyond Scotland: Across 2014-2020 NHS organizations and healthcare facilities outside of Scotland have contacted QMU in order to adopt research recommendations and materials derived from the research in waiting times reduction initiatives. For example, an English NHS trust, serving a population of 536,000, with 900 referrals per year, used QMU research to reduce waiting times and improve delivery of autism diagnosis services in 2018 [S10]. They reported that implementation of training and development activities directly derived from QMU research, applied across its entire children's workforce, led to reductions in waiting times, with 25% of all referrals receiving a diagnosis more quickly in 2018 [S10]. The developments have also led to an increased awareness of the presentation of girls with autism, increased training for staff, increased use of autism diagnostic tools, and a community of practice to maintain and develop practitioners skills [S10]. The main research website has also had international reach, as evidenced by 17,238 hits from 49 countries recorded in 8 months.

5. Sources to corroborate the impact

[S1] QMU research disseminated on Scottish Government websites

Confirms initial dissemination on influential Scottish Government policy website "Scottish Strategy for Autism" (date accessed 09/01/2017) and subsequent publication on main Government website alongside key report "The Scottish Strategy for Autism" (date accessed 14/09/2020). URLs and screen shots available.

[S2] Testimonial from Scottish Government's Senior Policy Manager for Autism and Learning Disabilities (2020)

Includes corroboration of Scottish government endorsements for QMU research and QMU diagnostic standards, nature and extent of the autism community of practice arising from QMU research and confirmation of appointments and funding arising from the QMU research. *Contact details & PDF available.*

[S3] Citations in influential international and national clinical guidelines

Examples of influential guidelines citing QMU autism research, including **Australian Clinical Guideline** "A National Guideline for the Assessment and Diagnosis of ASD in Australia" (2018) citing R3.3 & R3.4 (underpinning QMU research) and **SIGN clinical guideline** "Assessment, diagnosis and interventions for ASD" (2016) citing R3.1 (underpinning QMU research). *Verbatim excerpts available.*

[S4] Endorsement provided by Scottish Government Minister in keynote speech at national forum for excellence in autism practice

Presentation by the **Scottish Government Minister for Public Health and Sport (2014)**. Confirms endorsements provided by Scottish Government Minister in keynote speech at national forum for excellence in autism. *Verbatim transcript and URLs available* (date accessed 28.10.17). See also **[S2]**.

[S5] Peer reviewed evidence confirming reductions in waiting times and improved identification of females with autism

[S5.1] Rutherford et al (2018a). "Implementation of a practice development model to reduce the wait for Autism Spectrum diagnosis in adults." JOURNAL OF AUTISM AND DEVELOPMENTAL DISORDERS, 48(8), pp2677-2691. *PDF available.*

[S5.2] Rutherford et al (2018b). "Improving efficiency and quality of the children's ASD diagnostic pathway: Lessons learned from practice." JOURNAL OF AUTISM AND DEVELOPMENTAL DISORDERS, 48(5), pp1579-1595. *PDF available.*

[S6] Testimonial: Expert Practitioner & Manager, NHS Argyle (2020)

Corroborates significant local impacts and benefits associated with use of QMU research, including reductions in waiting times, and beneficial community of practice. *Contact details & PDF available.*

[S7] Testimonial: Lead for Autism Diagnostic Service, NHS Lanarkshire (2020)

Corroborates increased use of autism diagnostic instruments in the assessment pathway, impacts of training for practitioners in autism diagnosis instruments, and increase in capacity of expert staff to identify people with autism, based on QMU research. *Contact details & PDF available.*

[S8] Testimonial: Clinical Director for Community Child Health & Medical Lead for Autism Diagnostic Services, NHS Lothian (2020)

Corroborates impacts, including reductions in waiting times from application of QMU research, and improvement for females associated with QMU research. *Contact details & PDF available.*

[S9] Scottish Government Programme for Government 2019-2020

The **Scottish Government's 2019-2020 policy commitments** which reference the QMU autism research, as well as a statement of funding for a National Autism Implementation Team (directly based on recommendations from QMU) (page 100). *Verbatim excerpts available.*

[S10] Testimonial: Children and Young People's Commissioner, NHS Kernow (NHS England) (2019)

Corroborates significant influence of QMU research on reductions in waiting times, increased awareness of the presentation of girls with autism, increased training for staff, increased use of autism diagnostic tools, and the development of community of practice to maintain and develop skills. *Contact details & PDF available*