

INTEGRATED CARE Can collaborative working improve diabetic retinal screening rates in individuals also diagnosed with a severe mental illness?

Authors: Zoe S Sherwood,^A John Sandford^B and Sarita Jacob^C

ABSTRACT

Aim

We aimed to create a collaborative data sharing project between two NHS trusts to improve attendance and access to diabetic retinopathy screening in individuals with severe mental illness (SMI).

Methods

The eligible patient lists were analysed before and after interventions to assess their effectiveness over two data runs.

Results

Screening attendance rates increased by 31% and 25% in the data runs; a significant number of patients (15%) who were screened required onward referral to hospital eye services. Patient registrations increased from 35% to 86% for previously not registered individuals. Inpatients were around 50% more likely to get screened and registered than community patients.

Conclusion

Information sharing and collaborative working between services can improve patient health outcomes, increasing the number of eligible individuals with SMI registered and improving attendance. The project shows the potential for future data sharing collaborations, highlighting the need for further improvement, development and investment.

KEYWORDS: diabetes, health inequalities, retinal screening, collaborative care, severe mental illness

DOI: 10.7861/fhj.2022-0008

Introduction

On average, people diagnosed with a severe mental illness (SMI) die 15–20 years earlier than the general population,

which is often attributed to poor management or late diagnosis of physical health conditions.¹ Lifestyle choices, stigma and treatment-/condition-specific factors, in addition to uncertainty over whose remit physical health concerns belong to, all contribute to the increased likelihood of developing physical health comorbidities within this population group. Type 2 diabetes (T2D) is one of those physical health conditions, and a major public health issue in its own right.² Prevalence of T2D is reportedly 2–3 times higher in people with SMI than the general population.³ If left unmanaged, it increases the risk of chronic debilitating complications and early mortality. It is noted that, despite a higher risk of experiencing physical ill-health, individuals with an SMI diagnosis have less access to preventative and early interventions for physical illnesses.¹ In *No health without mental health*, a key objective was to ensure that more people with SMI achieved a good standard of physical health.⁴ As individuals diagnosed with poorly managed diabetes are at a higher risk of developing long-term physical health complications (such as sight loss) and those with SMI are more likely to be diagnosed with diabetes, the risks and complications associated with diabetes are pivotal in achieving this objective. Therefore, access to regular screening enabling detection and treatment of diabetes forms an important part of achieving this objective.⁵

It is estimated that diabetic retinopathy (DR) accounts for 4.8% of all cases of blindness, totalling 37 million individuals worldwide. It has been shown that, where countries have screening programmes, there is a decline in the prevalence and incidence of DR.⁶ When the Diabetic Eye Screening Programme was introduced in the UK in 2008, diabetic eye disease was the leading cause of sight loss in the working age population, however, this is no longer true.⁷ Early detection and prompt treatment of vision-threatening DR supports the reduction of diabetes-related visual impairment.⁸ In fact, early treatment can reduce the risk of severe visual loss by 57%.⁶ In contrast, delaying screening can adversely affect patient outcomes and the risk increases with the duration that an individual remains unscreened.⁹ Health leadership and partnership working is essential to maximise opportunities to improve access to screening, particularly in the vulnerable and minority population groups.¹⁰ This project was undertaken to improve attendance and access to diabetic retinopathy screening in individuals with SMI by partnership collaborative working.

Authors: ^Ainpatient diabetes specialist nurse, Birmingham and Solihull Mental Health NHS Foundation Trust, Birmingham, UK; ^Bretinal screener/grader, Birmingham, Solihull and Black Country Diabetic Eye Screening Programme, Birmingham, UK; ^Cophthalmology lead, Birmingham, Solihull and Black Country Diabetic Eye Screening Programme, consultant ophthalmologist, University Hospitals Birmingham NHS Foundation Trust, Birmingham, UK and honorary professor, Aston University, Birmingham, UK

Table 1. Diagnostic criteria for diabetes¹¹

Symptomatic	One of the three abnormal blood tests	<ul style="list-style-type: none"> > HbA_{1c} = 48 mmol/mol or above > Fasting plasma glucose = 7.0 mmol/L or above > Random plasma glucose = 11.1 mmol/L or above
Asymptomatic	Two of the three abnormal blood tests collected on different days	<ul style="list-style-type: none"> > HbA_{1c} = 48 mmol/mol or above > Fasting plasma glucose = 7.0 mmol/L or above > Random plasma glucose = 11.1 mmol/L or above
High risk of developing T2D	0 diagnostic results but abnormal range	> HbA _{1c} = 42–47 mmol/mol
Not diabetic	0 diagnostic blood tests	> HbA _{1c} < 42 mmol/mol

HbA_{1c} = glycated haemoglobin; T2D = type 2 diabetes.

Materials and methods

This was a quality improvement project completed after the review board approval (IG267) from the audit department of Birmingham and Solihull Mental Health NHS Foundation Trust (BSMHFT) complying with the Declaration of Helsinki. Necessary approvals were obtained from clinical and information governance departments of both hospital trusts for data sharing purposes.

BSMHFT patient data were analysed and a report compiled with details of individuals with glycated haemoglobin (HbA_{1c}) results of 48 mmol/mol or above. HbA_{1c} is a gold standard diagnostic blood test for diabetes, as detailed in Table 1.¹¹ Records were anonymised to include only NHS number, initials and date of birth and shared with Birmingham, Solihull and Black Country Diabetic Eye Screening Programme (DESP). DESP compared this data with individuals known to them. The spreadsheet was then colour coded, as detailed in Table 2.

Patients identified as overdue or never screened were split into community or inpatient groups. Inpatient groups were supported as part of their discharge and recovery planning to book and

Table 2. Coding and registration status for screening

Red	Never screened (known to DESP)
Amber	Overdue screening (known to DESP)
Green	Screened within previous 12 months (known to DESP)
Not registered	Unknown to DESP and possibly undiagnosed diabetes
No action needed	Known to DESP and within specialist ophthalmology clinics / opted out

DESP = Birmingham, Solihull and Black Country Diabetic Eye Screening Programme.

attend appointments. Community mental health teams were encouraged to provide booking information to individuals known to their caseload that were overdue screening and prompt them to attend and the 'not registered' patient records were reviewed to establish why. Records were updated and general practitioners (GPs) notified. The data were reviewed 6 months later to monitor any findings since adding prompts and support. A total of two new data runs were completed with both having a 6-month follow-up.

Results

The data results show similar values, as detailed in Table 3. There were 100 duplicate patients for data run 2 who were also present on data run 1; these were removed.

The data showed that 43/602 (7.1%) individuals had never attended a screening appointment. Alarming, 84/602 (14%) individuals were not registered or known to DESP, therefore, missing their opportunity for a screening invite. It was reassuring to note that 47% (283/602) individuals were up to date with their appointments. When this value is added to the no action needed group, 58.3% of all individuals identified were accessing appointments. The same data were reviewed 6 months later to note any differences that our interventions could have made. This was repeated for the second data collection set and collated (Fig 1).

The 6-monthly review conducted after each collection gave an indication of eye health of individuals known to DESP who had initially never been screened or were overdue and who had since attended; a total of 47 patients. Over the course of two data collections, seven (15%) of these individuals required referral to specialist eye clinics for follow-up treatments and closer monitoring. This is significant as it emphasises the importance for individuals to have support to attend screening services. The group of individuals that were not known to DESP could also be separated into confirmed and pending diagnosis groups. The confirmed group met the diagnostic criteria for diabetes, outlined in Table 1, whereas the pending group were asymptomatic individuals that did not yet meet these criteria.

The results identified individuals who subsequently became registered as a result of project interventions. This is significant as

Table 3. Screening figures for data runs

	Data run 1 individuals identified, n	Data run 2 individuals identified, n
Total number after deductions (deceased, out of area or not yet diabetic)	320	282
Total never screened (red)	23	20
Total overdue screening (amber)	68	56
Total screened in last 12 months (green)	153	130
Total not registered	41	43
Total no action needed (already known to specialist clinics within in-care ophthalmology)	35	33



Fig 1. Results of intervention after 6 months for data runs 1 and 2.

it shows that following the 6-monthly review of data run 2, 86% of individuals were registered and, out of those, 29% had attended a screening appointment. Individuals within inpatient services were noted to be 50% more likely to get screened in both the 'never screened' and 'overdue screening' sections (data run 1: 22/44; data run 2: 22/59). Inpatients were similarly around 50% more likely to get registered in the 'not registered' section (data run 1: 37/71; data run 2: 33/70).

Discussion

It is interesting to compare results depending on whether an individual is being supported within inpatient or community services. The inpatient cohort will be assisted with booking appointments, arranging transport and escorted to appointments. It was noted that those individuals were 50% more likely to get screened when compared with those within community services. BSMHFT benefited from employing an inpatient diabetes specialist nurse who was able to share information to both the individual and staff supporting them. In most cases, retinal screening was included in discharge planning. It leads to the conclusion that if community patients were provided with this additional support, then a significantly higher number of individuals would attend appointments. Unfortunately, part of the limitations of this project was that the BSMHFT inpatient diabetes specialist nurse was unable to offer the same level of support and information to community teams, as those with a diagnosis of diabetes would fall under the remit of primary care.

A streamlined system for analysing the 'not registered' list and contacting GPs made a significant difference to the number of individuals registered at the second 6-month review; increasing from 35% to 86%. These results emphasise how information sharing has potential to improve long-term health outcomes and reduce the number of individuals omitted from screening programmes. This information highlights the difficulties with multiple systems within the NHS, as all data used were already available, it just needed connecting. Throughout the project, several additional themes recurred.

Language and deprivation

There is a wide range of ethnicities and cultures within the Birmingham, Solihull and Black Country local population, with more than 40% of the cohort identifying from Asian or Black backgrounds. Data gathered locally in 2015 showed that areas with the poorest screening uptake were found to have higher deprivation scores. Within those areas, almost half of

the population were born overseas and would have English as a second language, if spoken at all. It is known that having a limited standard of English literacy proficiency is associated with poorer glycaemic outcomes, higher rates of non-adherence to medications and an increase in medical emergencies.¹² BSMHFT were able to share information regarding whether a translator was required and, if individuals were within inpatient services, they would be supported to access the appointment system. Provision of multi-lingual resources and identifying when they are required would be a huge benefit to preventative screening services.

Open invite system / accessibility

Being on an open invite system can be positive in providing flexibility and patient choice, but it poses issues for individuals who are not able to book an appointment, such as those who do not speak sufficient English. For these individuals, somebody needs to call on their behalf, arrange the appointment, transport and possibly escort them to the appointment. This is a considerable burden. Appointments are often within standard working hours at hospital sites, with fewer appointments during the weekends. This may cause difficulties if an individual requires support to book and attend appointments. Screening models can differ across the country, which can cause confusion for those individuals who live close to area boundaries. It is noted that preferences for a closed or open invite system differed among specific demographics, thus, one system does not suit all.¹³

Anxiety

Anxiety about appointments is common prior to first screening visits, regardless of SMI status. The uncertainty and anxiety about dilating drops and possible discomfort / blurry vision can be a factor in non-attendance. This could be amplified for patients with SMI, especially if they have anxiety about healthcare settings in general. An earlier study highlighted that individuals with SMI were often disengaged with their diabetes care and that anxiety regarding the eye drops contributed to non-attendance.⁹ These findings are similar to another study, advising that individuals with a diagnosis of SMI were significantly less likely to attend preventative screening programmes.¹⁴ Social factors such as lack of trust in healthcare professionals, stigma associated with a SMI diagnosis, individuals emotional state and fear associated with receiving bad news can impact on attendance.¹⁵ Witnessing family members with diabetes complications sometimes causes individuals to avoid screening due to fear of receiving bad news.⁹ DESP have noted that with reassurance and support from carers and people they trust,

individuals usually have a positive screening experience and are more likely to attend subsequent appointments.

Beliefs

Some cultural and religious beliefs override successful diabetes management as individuals believe it is 'God's will'.¹⁶ Individuals may believe that diabetes is a punishment and they cannot do anything to alter this, while other cultural beliefs may use prayer to protect from the complications of diabetes.¹² Some cultural/health beliefs do not recognise diabetes as a serious medical condition, but rather 'a touch of sugar'.¹⁷ Diabetic eye disease is often asymptomatic, therefore, individuals would have no idea that they have sight threatening retinopathy unless they attended their screening appointment.¹⁸ An ophthalmic study into non-attendance in the UK found that lack of awareness was the greatest barrier to attendance. Patients were aware that diabetes could affect the eye, but not that it could lead to blindness or that severe retinopathy could be asymptomatic.¹⁹ The DESP/BSMHFT study noted that individuals may not be aware that diabetic eye screening is free regardless of benefit status. This supports a previous study highlighting that perceived financial implications were one of the most frequently reported barriers to screening attendance.¹⁵ If diabetes diagnosis and risks are not recognised, then engagement with related screening programmes will be low.

Support

As shown in earlier comparisons regarding inpatient and community individuals, most of these barriers (language, booking process, transport and attendance support) were addressed by inpatient staff, resulting in improved attendance. This is supported by a study that concluded that people living with SMI require additional support to access preventative health programmes.⁵ Therefore it is likely that extending the availability of support to community environments would have the same impact on engagement and attendance.

Data/results sharing

The NHS does not operate on a uniform records system so access to records and test results held by each trust/service was a major barrier. Specific treatments (such as the anti-psychotic medication clozapine) require close and continued monitoring, which is the responsibility of the prescribing trust and not the GP. Without access to all blood test information, this could be the difference between a diagnosis of diabetes or being identified as being at high risk, thus potentially impacting on patient experience and consistency of care. In the community, there may be concordance issues as individuals will sometimes engage enough to avoid recall to inpatient services, but the legislation does not cover physical health issues. There is also a grey area of debate as to whether physical health conditions resulting from mental health treatments are the responsibility of the mental health trust or primary care GP, and this division has yet to be fully resolved, potentially causing a 'black hole' of health data. Within the SMI population individuals may spend periods of time within inpatient services, frequently changing address and GP, meaning that they simply get lost in the system as non-attenders even though they may not have received the invite.⁹

Table 4. Barriers identified and recommendations to improve health screening services

Barriers	Recommendations
Language	<ul style="list-style-type: none"> > At first contact, ensure language preference is recorded. > NHS appointment letters and information automatically translated if language preference specified.
Open invite system	<ul style="list-style-type: none"> > Increase awareness of access to retinal screening service regardless of benefit status. > Review availability and location of retinal screening appointments.
Anxiety	<ul style="list-style-type: none"> > Increase social prescribing roles to assist vulnerable population groups. > Collaboration between trusts to increase awareness and reassurance of screening (eg Making Every Contact Count).
Beliefs	<ul style="list-style-type: none"> > Increase in social prescribing roles for vulnerable population groups, including outreach services. > Collaboration between trusts to increase awareness and reassurance of screening (eg Making Every Contact Count). > Collaboration between trusts and local religious institutions.
Support	<ul style="list-style-type: none"> > Increase in social prescribing roles for vulnerable population groups. > Development of a mental health – physical health link for health inequalities.
Data sharing	<ul style="list-style-type: none"> > Development of a robust data sharing system between services; for example, blood tests, patient address, patient GP, inpatient/community status, date of last screening appointment and frequency of recall. > Collaborative working between NHS trusts to improve long-term health outcomes.
Investment	<ul style="list-style-type: none"> > This project has shown potential to improve screening uptake, however, investment is required to continue and develop joint working. Due to generalisability, the project has the potential to be expanded among other trusts and screening specialisms. > A process to bridge the gap in physical health in SMI populations, particularly in community settings. > Expansion of physical health specialties within mental health inpatient settings.

GP = general practitioner; SMI = severe mental illness.

Recommendations

This project has potential to improve health screening services (Table 4) among differing population groups and NHS trusts, the overall approach could also be implemented across differing specialisms due to its generalisability.

Limitations

This project was undertaken to provide evidence to support investment into preventing any barriers identified to accessing and engaging with DESP. As a result of this, the potential for detailed statistical analysis and development of topics in areas, such as inpatient/community services and ethnicity, was highlighted. The project was completed in addition to usual full-time working responsibilities, with limited time, resources and skill mix. These practical limitations could be easily removed with future investment.

Conclusion

This study provided evidence that collaborative working between NHS trusts can increase attendance to screening appointments in SMI population groups, thus, positively impacting on long-term health outcomes. The project was able to show that individuals were 50% more likely to attend screening appointments if they received additional support with booking and attendance. The numbers registered for screening during the course of this project saw an 86% increase in the 'not registered' cohort, with successful identification of barriers and obstacles to screening. Increased awareness of patient-level barriers may be used by other screening programmes to provide a more accessible service, which is certainly a major consideration for any future projects.

Finally, the project led us to conclude that parity of esteem between NHS services requires further improvement and development. Equality and equity are not the same. To enable individuals within vulnerable population groups to access the same opportunities for healthcare-related screening, we cannot offer the same level of service as the general population. The current service may be equal, but it is not accessible to all. Until this is addressed, health inequalities will continue to influence patient care and outcomes. ■

Acknowledgements

We would like to thank the service users, carers and families for their feedback and support in identifying barriers to attendance of screening services.

References

- Public Health England. *Severe mental illness (SMI) and physical health inequalities*. London: Wellington House, 2018. www.gov.uk/government/publications/severe-mental-illness-smi-physical-health-inequalities/severe-mental-illness-and-physical-health-inequalities-briefing
- World Health Organization. *Global report on diabetes*. WHO, 2016.
- Hayes JF, Marston L, Walters K *et al*. Mortality gap for people with bipolar disorder and schizophrenia: UK based cohort study 2000-2014. *Br J Psychiatry* 2017;211:175-81.
- Department of Health. *No health without mental health*. London: Waterloo Road, 2011. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/138253/dh_124058.pdf
- Bradley ER, Deffalon V. Diabetic Retinopathy Screening in persons with mental illness: a literature review. *BMJ Open Ophthalmol* 2020;5:e000437.
- Ting DSW, Cheung GCM, Wong TY. Diabetic retinopathy: global prevalence, major risk factors, screening practices and public health challenges: a review. *Clin Exp Ophthalmol* 2015;4:260-77.
- Scanlon PH. The English National Screening Programme for diabetic retinopathy 2003 - 2016. *Acta Diabetol* 2017;54:515-25.
- Harris M. *The NHS diabetic eye screening programme: new common pathway*. The Royal College of Ophthalmologists, 2012.
- Rahmen F, Zekite A, Bunce C *et al*. Recent trends in vision impairment certifications in England and Wales. *Eye* 2020;34:1271-8.
- Public Health England. *NHS population screening: improving access for people with severe mental illness*. PHE, 2021. www.gov.uk/government/publications/population-screening-access-for-people-with-severe-mental-illness/nhs-population-screening-improving-access-for-people-with-severe-mental-illness
- World Health Organization. *Use of glycated haemoglobin (HbA1c) in the diagnosis of diabetes mellitus*. WHO, 2011. www.who.int/diabetes/publications/report-hba1c_2011.pdf
- Rebolledo JA, Arellano R. Cultural differences and considerations when initiating insulin. *Diabetes Spectrum* 2016;29:185-90.
- Orton E, Forbes-Haley A, Tunbridge L *et al*. Equity of uptake of a diabetic retinopathy screening programme in a geographically and socio-economically diverse population. *Public Health* 2013;127:814-21.
- Kilbourne AM, Pirraglia PA, Lai Z *et al*. Quality of general medical care among patients with SMI: Does colocation of services matter? *Psychiatr Serv* 2011;62:922-8.
- Lu Y, Serpas L, Genter P *et al*. Divergent perceptions of barriers to diabetic retinopathy screening among patients and care providers, Los Angeles, California, 2014-2015. *Prev Chronic Dis* 2016;13:E140.
- Patel NR, Chew-Graham C, Bundy C *et al*. Illness beliefs and the sociocultural context of diabetes self-management in British South Asians: a mixed methods study. *BMC Family Pract* 2015;16:58.
- Swaleh RM, Yu C. "A touch of sugar": A qualitative study of the impact of health beliefs on type 1 and type 2 diabetes self-management among black Canadian adults. *Can J Diabetes* 2021;45:607-13.
- Beaser RS, Turell WA, Howson A. Strategies to Improve Prevention and Management in Diabetic Retinopathy: Qualitative Insights from a Mixed-Methods Study. *Diabetes Spect* 2018;31:65-74.
- Strutton R, Chemin AD, Stratton IM *et al*. System-level and patient level explanations for non-attendance at diabetic retinopathy screening in Sutton and Merton: A qualitative analysis of a service evaluation. *BMJ Open* 2016;6:e010952.

Address for correspondence: Mrs Zoe S Sherwood, C/O MPFT, Diabetes Specialist Team, 5th Floor, Civic Centre, Beecroft Road, Cannock WS11 1BG, UK.
Email: zoe.sherwood@mpft.nhs.uk
Twitter: @SherwoodZs