

Title: An evaluation of a pilot community-based glaucoma check service in Hackney, London, UK.

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Running head: An evaluation of a glaucoma check service.

Abstract:*Purpose:*

To evaluate the feasibility and acceptability of a pilot glaucoma check service based in general practice. The service was optometrist-led and targeted people of Black Caribbean and Black African descent aged 40-65 years, resident in Hackney, London, UK and registered with one of four participating practices.

Methods:

Analysis of service data; a patient survey; a prospective audit of secondary care referrals; a cost-consequence analysis; and interviews with staff involved in developing and implementing the service.

Results:

3,040 patients were invited to undergo the free check; 595 (19.6%) booked an appointment and 461 (15.2%) attended. 243 of the 461 attendees completed a survey (response rate 52.7%). Only 62.4% indicated in the survey that their last eye test was within the two years; 11.4% of women and 16.0% of men reported that they had never had an eye test. Following the check, 31 patients (6.8%) were referred to secondary care, 22 attended and were assessed for glaucoma. Of those assessed, four were diagnosed with glaucoma and eight with suspected glaucoma, i.e. 2.6% of patients who underwent the glaucoma check were identified as having either glaucoma or suspected glaucoma.

Conclusion:

This study represents one possible configuration for a glaucoma case finding service, and it contributes to a wider debate about whether screening, targeted or otherwise, should be

provided in the UK. Our findings suggest that that general practice was an acceptable setting and the service may have reached some people who were not previously engaged with primary eye care services.

Introduction

Glaucoma is one of the most common causes of blindness worldwide [1], and is second only to macular degeneration as the leading cause of blindness in the UK [2]. Open angle glaucoma (OAG) is the most widespread form [1], and early detection and timely treatment are important in order to delay disease progression and prevent visual impairment [3].

Currently, referrals to hospital eye services are made by community optometrists who identify suspected cases when conducting routine eye examinations [4, 5], a system which is thought to work against early diagnosis in most cases [6]. It is estimated that half of prevalent glaucoma cases are undetected [1] and, consequently, population-based screening programmes have been explored. The most recent review by the UK National Screening Committee (NSC) concluded that glaucoma met some but not all of the criteria for a national screening programme [7]. A particular issue is that diagnosis depends on expert opinion, as no single test or combination of tests can discriminate between individuals with and without OAG [8]. Relatedly, the number of 'false positive' referrals for suspected glaucoma to hospital eye clinics has been highlighted as a concern in terms of secondary care capacity [9, 10]. A Health Technology Assessment (HTA) concluded that an optimal strategy for testing had yet to be identified, but modelling suggested that while screening was unlikely to be cost-effective for the general population, targeted screening for high risk groups such as people of Black Caribbean and Black African descent may be [6, 11]. Prevalence in this group is estimated to be nearly double that of the general population, at 3.9% (ranging from 1.2% in those aged under 50 years to 8.2% in those aged over 60) [12].

A targeted screening programme for glaucoma could be designed in different ways; considerations include the tests used, the personnel involved, the setting, and the population targeted. Using a Delphi process, Campbell et al [13] advanced a set of screening options,

including initiation of screening at age 50, with a combination of two or three tests conducted by an ophthalmically-trained technician in a community setting. However, questions remain regarding which groups to target as well as the feasibility and acceptability of a potential programme [13].

In this paper we report the results of an evaluation of a pilot glaucoma check service in Hackney, London, UK. It was an optometrist-led service, based in general practice and targeted people of Black Caribbean and Black African descent aged between 40 and 65 years. The service was developed by Hackney and City Primary Care Trust (PCT) in conjunction with Royal National Institute of Blind People (RNIB) to investigate the feasibility and acceptability of this service configuration which would not be possible to assess through modelling. To our knowledge, it is the first targeted glaucoma check service to have been piloted in the UK.

The intervention

An advisory group - consisting of representatives of the PCT, optometrists, ophthalmologists, RNIB, the evaluation team and a service user - decided upon the service model during several development workshops in which the findings of locally conducted formative research were considered.

The pilot service ran for six months, from October 2012 to March 2013. Four GP practices took part, one of which hosted the service (Practice A). The other three practices (B, C, and D) were situated within 1.5 miles of the host practice. Each practice identified and wrote to all their eligible patients (aged 40 to 65 years, of Black Caribbean and Black African descent, and with no existing glaucoma diagnosis) with an information leaflet inviting them to make an appointment to attend for a glaucoma check at the host practice. In two of the practices (A and B), a reminder letter was sent to those who did not respond to the initial invitation. A

random half of patients from Practice A who did not respond to the postal invitations were allocated to be contacted by telephone and invited to make an appointment.

The glaucoma checks were performed by sessional optometrists. Several sessions a week, including on Saturdays, were offered in order to provide a mix of appointment times. The check consisted of a standard automated visual field test using Humphreys Visual Field Analyser, an intraocular pressure (IOP) measurement using Goldmann Applanation tonometry, and optic nerve head analysis using photographic imaging assessing the clinical features. Clinical protocols were developed for governance and quality assurance purposes. Regular audits of care were conducted by an RNIB optometrist and the optometric advisor from Hackney and City PCT. Patients identified as potential glaucoma cases (Box 1) were referred to Moorfields Eye Hospital for investigation. Patients requiring a recheck (Box 1) were invited back within two weeks to re-run the procedures.

Evaluation methods

Evaluation of the pilot included analysis of service data, a patient survey, a prospective audit of referrals, a cost-consequence analysis, and interviews with staff involved in developing and implementing the service.

- 1) *Service data*: Anonymised activity data relating to each person invited were analysed to determine key project outcomes, including uptake of the service, non-attendance (DNA) and referrals to secondary care.
- 2) *Prospective audit*: We conducted an audit of patients referred to secondary care via the pilot service. Classificatory (sex, age, ethnicity and post code) and clinical (intraocular pressure, optic nerve damage, visual fields, visual acuity and diagnosis) information was collected.

- 3) *Patient survey*: All patients attending the service were invited to complete a survey which included questions about their eye care history and experience of the service.
- 4) *Cost-consequence analysis*: Costs of staff, equipment, room hire, and consumables were calculated from the project budget and expenditure reports.
- 5) *Interviews with staff*: In order to investigate the processes of developing and implementing the project, we conducted seven face-to-face, semi-structured interviews with staff involved in its design and delivery. Interviews were audio recorded, transcribed verbatim and analysed by the evaluation team.

Ethics

The evaluation was approved by the London School of Hygiene and Tropical Medicine Ethics Committee (reference number 5957), the National Research Ethics (NRES) Committee London Bromley (reference number 11/LO/1264), and NHS East London & City Primary Care Trust (reference number RD/022).

Results

- 1) *Service uptake*: 3040 patients with a mean age of 49.0 years were identified from the patient records of the four participating practices and invited to attend the free glaucoma check (Table 1). Based on data provided by two practices,¹ a slightly higher proportion of women (53.2%) were invited. 595 (19.6%) patients made an appointment, of whom 59.6% were women. 461 (15.2%) attended (58.9% women) and 134 patients did not

¹ Anonymised data on the sex and age of those invited to access the service were only available from two of the participating practices. The other two practices were not able to provide this data due to a change in information systems during the project. Information on sex and age of those accessing the service was requested from patients when they telephoned to make an appointment.

attend (DNA) their appointment (63.2% women). Uptake was highest among patients from the host practice (Practice A) (Table 1).

75 patients (16.3% of those who attended the initial check) were invited back to undergo a recheck (Figure 1). Of these, 56 attended (74.7%), of whom nine patients (16.1%) were referred to secondary care. Among those who did not require a recheck, 22 patients were referred directly to secondary care for further investigation (5.7%); nine (2.0%) were referred back to their GP with other eye complaints, e.g. cataract or dry eye; and one was unable to complete the test due to facilities being inaccessible.

2) *Prospective audit:* In total, 31 patients (6.8% of those attending the check) were referred to Moorfields via the service. One was registered at the hospital reception but wasn't seen by the consultant and so no outcome was recorded and this patient has been excluded from our analysis. A further two patients were referred to, and seen in, the cataract clinic. Of the remaining 28, six (21.4%) did not attend their appointment. This means 22 patients attended the hospital appointment and were assessed for glaucoma. Of these, 12 (54.5%) were diagnosed with glaucoma (n=4) or with suspected glaucoma (n=8) (Table 2), i.e. 2.6% of patients who underwent the free glaucoma check (12/461) were identified as having glaucoma or suspected glaucoma. Prevalence was higher among men than women (3.2% and 2.1% respectively). Of the four patients diagnosed with glaucoma, three presented at a 'moderate' stage of disease, and one presented at a 'severe' stage (Table 3). Of the 22 patients who attended, one was found to have ocular hypertension and nine (40.9%) were found to have no evidence of glaucoma and discharged.

3) *Patient survey:* Of the 461 patients who attended the glaucoma check, 243 (52.7%) completed a questionnaire. The mean age of respondents was 49.9 years, and a higher

proportion of women (57.9%) completed the questionnaire, in line with proportionally more women attending the service. 96.7% of respondents agreed with the statement that overall their experience of attending the glaucoma check was a positive one. 62.4% reported having an eye examination in the last two years while 11.4% reported never having had one; a higher proportion of men (16.0%) than women (7.5%) reported that this was the case ($p = 0.02$) (Table 4).

44 patients (18.9%) reported a family history of glaucoma, with a higher proportion of women (23.1%) than men (13.1%) doing so ($p = 0.090$). Half (51.1%) of patients reporting a family history of glaucoma had not been for an eye test in the last year (as is recommended by guidelines) and six (13.3%) reported that they had never had an eye test.

4) *Cost consequence analysis:* We calculated the total cost of the six month pilot service to be £108 161, including one-off project start-up costs (e.g. leaflet design and production, legal fees, project management) and ongoing costs (staffing, equipment, room hire, and consumables). Staffing accounted for 62% of the total and, of this, 42% was clinical staff time. The cost per patient identified at Moorfields with suspected or definite glaucoma was £9 013. We further estimated that the cost of an ongoing service over a six month period would be £90 179 (without initial set-up expenses, assuming a reduction in project management and administration time, and equipment bought or leased longer term). The cost per person identified with glaucoma in this scenario fell to £7 515. We also calculated that if the clinic was running at full capacity, as would be possible in an established service, 20% more people could be seen. The number of referrals to Moorfields would increase as would the number of new cases detected. In this model, the cost per person identified could reduce further to £6 219.

5) *Interviews with staff:* Interview participants talked about the development phase, shared their views on the enablers and challenges of the operational phase, and reflected on the service model. *Development phase:* Those interviewed who were involved in the development of the project raised concerns about the potential number of patients referred to secondary care via the service who on further investigation would be found to have no evidence of glaucoma (i.e. the false positive rate). Minimising false positives informed the decision to employ optometrists rather than technicians to conduct tests, the type of tests used and, specifically, photographic imaging of the optic nerve. *Operational phase:* Participants noted that the intervention was completed on time and to plan, and felt that significant enabling factors were the expertise of optometrists, commitment of staff involved at the PCT and GP practices, acknowledging that much rested on the support provided by the host practice. It was thought that more staff time would have been advantageous, especially administrative and technological support, and more project management staff time during the development phase of the project could have reduced pressure on those involved. Staff reported technical problems with the camera used for assessing optic nerve head images, which meant that photographs could not be emailed to consultants at Moorfields to check before referral to secondary care. *Reflections on the model:* Interview participants felt that patients attending might be the most conscientious who routinely attend optometrist appointments rather than hard-to-reach patients. They did not characterise the service as being quick, simple or cheap. The visual field test, for example, which took 15-20 minutes to complete, was not seen as a good use of optometrist time and it was suggested that this could have been done by a technician.

Discussion:

One in five patients who were invited to attend the service made an appointment and, of these, four out of five attended. Uptake was highest in the host practice, and more women than men made appointments. The service resulted in 31 patients being referred for further investigation, and just over one third of these received a diagnosis of suspected or definite glaucoma. Our survey found that patient satisfaction with the service was high, and staff interviews highlight general practice as an acceptable location to host a service.

To our knowledge, this study is the first targeted glaucoma check service to be piloted in the UK which seeks to answer questions about implementation of a service not possible with previous theoretical work. The evaluation took a mixed methods approach, with both quantitative and qualitative data collected by an independent research team. A limitation was the survey response rate; just over half of those attending the service completed the survey, and so the possibility of participation bias cannot be excluded. Further, as this was a pilot, service-level data collection mechanisms were somewhat underdeveloped; a spreadsheet was used rather than a dedicated database resulting in less efficient data collection. There were also limitations with respect to the service; principal amongst these were the fact that it only ran for six months due to NHS changes at the time, and processes for reducing and following up DNAs were under-developed. Reported costs are high, as they include one-off set up costs, as well as equipment hire which was more expensive than if hired long term or purchased. Also, we cannot comment on the appropriateness of such a model for different populations; Hackney has a distinct demography unlikely to be replicated in non-inner city areas.

As this is the first such programme undertaken in the UK, we cannot compare uptake with that of other studies. Prior et al's study [14] to identify factors associated with intention to

attend a hypothetical eye health check for glaucoma found that a large proportion of their sample were highly receptive to the idea of an eye health programme to detect glaucoma. For this pilot service, there was minimal promotion of the project or glaucoma awareness raising locally, something which might be helpful in encouraging uptake in future interventions elsewhere. Uptake was highest in the host practice amongst those who received the invitation and reminder letters, and the addition of a telephone call to those who had not responded to the initial invitation and reminder resulted in another 39 people booking an appointment. In future interventions, a centralised location familiar to patients and a budget to cover reminder calls could be considered.

Analyses of patient characteristics show that a slightly higher proportion of women were invited to attend the glaucoma check, and women were also more likely to take up the offer. Despite fewer men than women passing through the service at each stage of the process, more men were diagnosed with glaucoma, suggesting men as a potentially hard-to-reach group who may benefit from a service such as this. Generally, prevalence estimates were lower than anticipated, and may reflect the relatively young age of the target group. In a Swedish study, 1.23% of a general population sample were diagnosed with previously undetected glaucoma [15], and prevalence was found to increase with age. It is also likely that, due to a quarter of patients DNA recheck appointments, potential cases were 'missed' - 1 in 7 patients who underwent a recheck were referred (compared to approximately 1 in 16 who did not need a recheck). Those who were diagnosed with glaucoma presented at a moderate stage of the disease, and one person was found to have severe glaucoma. It is possible that these people were 'residual' cases which had not been picked up through the existing system and, in the future, if a service were to become 'embedded' and running for a longer period of time, moderate, advanced, and severe cases would be less frequently

identified in favour of early or suspected cases. No one was found to have an early stage of glaucoma, although eight people had suspected glaucoma and will continue to be monitored.

From the outset, a major concern of those involved in the design of the service was the potential number of patients who might be referred to secondary care who on further investigation were found to have no evidence of glaucoma. This concern, and the need to mitigate against it, informed the development of the service model. The model included a recheck for patients whose tests were inconclusive in the first instance, and a review of optic nerve images by a consultant. As noted previously, approximately 1 in 7 patients who underwent a recheck were referred to secondary care, thus reducing the number of cases who would otherwise have likely been referred on the basis of inconclusive tests. However, the false positive rate in this pilot was similar to that seen in referrals from community optometrists [5], which may in part be due to the camera for reviewing optic nerve images not being functional for the majority of the pilot.

Another concern was whether the service would engage with those not routinely attending community optometry. Despite interview participants' suggestion that patients attending were the most conscientious who routinely attended optometrist appointments, a quarter of men who completed the survey had never had an eye examination or the last one was over five years ago. Also, nearly one in five of patients reported a family history of glaucoma but only half of these had been for an eye examination in the last year, as is recommended [16], and six of these patients had never had their eyes tested. These findings suggest that this pilot service may have reached some people at risk who have not previously engaged with primary eye care services. However, coverage is an important parameter of any screening programme and, due to the limited capacity of this short pilot service, we cannot conclude that this model will be able to access hard-to-reach populations in general. Other questions

remain, notably about the model itself and whether tests should be carried out by an optometrist or a technician. Future research would need to further consider these questions and others such as which age groups should be targeted; which tests should be performed; where services should be offered; and how to increase uptake, specifically among men and people with a family history of glaucoma. Cost-effectiveness, using trial data, would need to be estimated and the various options modelled, ensuring that outcome data (such as stage of presentation) are captured and analysed.

Implications:

Glaucoma prevalence is set to rise due to an aging population. There is a consensus among experts that early diagnosis is of high importance, both for patient quality of life and to alleviate pressure on secondary care services. With more research, targeted population screening may offer a cost-effective and also feasible alternative to opportunistic case finding.

Conclusion:

This study represents one possible configuration for a glaucoma case finding service, and it contributes to a wider debate about whether screening, targeted or otherwise, should be provided in the UK. Our findings suggest that this check service may have reached some people at risk who were not previously engaged with primary eye care services, and that general practice is an acceptable setting for such a service.

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References:

1. Quigley, H.A. and A.T. Broman, The number of people with glaucoma worldwide in 2010 and 2020. *British Journal of Ophthalmology*, 2006. **90**(3): p. 262-267.
2. Bunce, C., W. Xing, and R. Wormald, Causes of blind and partial sight certifications in England and Wales: April 2007-March 2008. *Eye*, 2010. **24**(11): p. 1692-1699.
3. Maier, P.C., et al., Treatment of ocular hypertension and open angle glaucoma: meta-analysis of randomised controlled trials. *BMJ : British Medical Journal*, 2005. **331**(7509): p. 134-134.
4. Sheldrick, J.H., et al., An analysis of referral routes and diagnostic accuracy in cases of suspected glaucoma. *Ophthalmic Epidemiol*, 1994. **1**(1): p. 31-9.
5. Bowling, B., S.D. Chen, and J.F. Salmon, Outcomes of referrals by community optometrists to a hospital glaucoma service. *Br J Ophthalmol*, 2005. **89**(9): p. 1102-4.
6. Burr, J.M., et al., The clinical effectiveness and cost-effectiveness of screening for open angle glaucoma: a systematic review and economic evaluation. *Health Technol Assess*, 2007. **11**(41): p. iii-iv, ix-x, 1-190.
7. Pittam, G., Allaby, M., Screening for Glaucoma: A draft report for the UK National Screening Committee. 2015, Solutions for Public Health.
8. Mowatt, G., et al., Screening Tests for Detecting Open-Angle Glaucoma: Systematic Review and Meta-analysis. *Investigative Ophthalmology & Visual Science*, 2008. **49**(12): p. 5373-5385.
9. NICE, NICE Clinical Guidance 85: Diagnosis and management on chronic open angle glaucoma and ocular hypertension. 2009, National Institute of Clinical Excellence.
10. Ratnarajan, G., et al., The effectiveness of schemes that refine referrals between primary and secondary care—the UK experience with glaucoma referrals: the Health

Innovation & Education Cluster (HIEC) Glaucoma Pathways Project. *BMJ Open*, 2013. **3**(7).

11. Hernandez, R.A., et al., Economic evaluation of screening for open-angle glaucoma. *Int J Technol Assess Health Care*, 2008. **24**(2): p. 203-11.
12. Wormald, R.P.L., et al., The African Caribbean eye survey: Risk factors for glaucoma in a sample of African Caribbean people living in London. *Eye*, 1994. **8**(3): p. 315-320.
13. Campbell, S.E., et al., Developing the specifications of an open angle glaucoma screening intervention in the United Kingdom: a Delphi approach. *BMC Health Serv Res*, 2012. **12**: p. 447.
14. Prior, M., et al., Evidence base for an intervention to maximise uptake of glaucoma testing: a theory-based cross-sectional survey. *BMJ Open*, 2012. **2**(2).
15. Heijl, A., B. Bengtsson, and S.E. Oskarsdottir, Prevalence and Severity of Undetected Manifest Glaucoma: Results from the Early Manifest Glaucoma Trial Screening. *Ophthalmology*, 2013. **120**(8): p. 1541-1545.
16. NHS. How often can I have a free NHS eye test? 2015 [cited 2015 04.08.15]; Available from: <http://www.nhs.uk/chq/Pages/1093.aspx?CategoryID=68&SubCategoryID=157>.
17. Mills, R.P., et al., Categorizing the Stage of Glaucoma From Pre-Diagnosis to End-Stage Disease. *American Journal of Ophthalmology*, 2006. **141**(1): p. 24-30.