Commentary

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Why 'case finding' is bad science

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Introduction

Since 1996, the UK National Screening Committee has independently assessed claims made for population screening and ensured NHS screening programmes deliver equity of access, net benefit without excess harm, and cost-effectiveness. The National Institute for Clinical Excellence began in 1999 to reduce variation in availability and quality of NHS treatment and care. Good Medical Practice has always been concerned about evidence-based practice. We are concerned that these safety mechanisms have been overridden by two contemporary developments: first, initiatives which promote screening despite a lack of consideration or approval by these bodies; and second, use of terms like 'opportunistic testing' or 'case finding' rather than screening, which are essentially euphemisms. We argue that these developments are regressive, result in potential inequity, and bypass the long established safety inherent in scrutiny and governance from the organisations designed to protect the public from non-evidence-based screening programmes.

The 1968 Wilson and Jungner criteria[1] for evaluating screening were incorporated by the UK National Screening Committee at its inception. These criteria appraise the viability, effectiveness and appropriateness of population screening programmes. They are necessary, as harm through screening is expected and requires balancing against the potential for benefit and cost-effectiveness. More broadly, harm through low value screening to populations may occur when resources to fund it are redistributed away from higher value care. The UK National Screening Committee recommended screening programmes are independently audited and reviewed, with integral quality control and an emphasis on equality of access to the target population.

The last decade has seen a panoply of initiatives and schemes described as 'case finding' or 'targeted screening' which have not been approved by the UK National Screening Committee (Table 1) and include dementia screening, lung cancer screening and atrial fibrillation screening.

We review this shift, highlight concerns that case finding is being used euphemistically for screening and explain our caution against the implementation of de facto population screening programmes which have not been considered or approved by independent, authoritative bodies such as the UK National Screening Committee.

'Case finding is not screening'

In 2013/2014, a Locally Enhanced Service (LES) was agreed between the British Medical Association and the Department of Health for memory testing on all people aged over 75 years, people aged over 60 years with known cardiovascular disease, people aged over 40 years with Down's syndrome and all people with known neurodegenerative conditions. General practitioners were paid according to how many people were tested.[2]

Intense debate followed. A group of doctors, including the National Clinical Director for Dementia, wrote that

> the proposals are not for screening but legitimate clinical case finding in groups of people known to be at risk of dementia…We agree that screening for Alzheimer's disease (where a diagnostic test is carried out on a population) is not appropriate and as such the proposals are not 'directly contrary to' the UK National Screening Committee advice.

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Table 1. Examples of UK screening programmes that have not been approved by UK National Screening Committee or NICE.

Dementia screening in primary care	Locally enhanced service offered to GPs in England 2013–2015 for all over-75s and 'at-risk' groups.[2]
Screening for atrial fibrillation	Via local initiatives/Imperial College Health Partners: all adults, particularly those aged over 65 years[3]
Lung cancer screening	Ever smokers aged 55–74 in deprived areas of Manchester, now rolled out to sites in Greater Manchester[4]
Chlamydia screening	All 'young adults'[5]
Heart age tool	Adults aged over 30 years in England[7]

Doctors were expected to ask patients – attending on unrelated issues – about their memory. Notably, in 2015, the UK National Screening Committee upheld previous recommendations against screening everyone aged 65 years and over for dementia, as there was concern that earlier diagnosis would not slow or prevent the disease, or make a substantial difference to outcomes.[9]

The proponents of 'case finding' of dementia suggested that case finding does not constitute screening when performed in at-risk groups. Yet, Wilson and Jungner defined terms:

> Mass screening: This is a term used to indicate the large-scale screening of whole population groups. We have used it to refer to screening where no selection of population groups is made.
>
> Selective screening: We use this term for the screening of selected high-risk groups in the population. It may still be large-scale, and can be considered as one form of population screening.

They go on to write: 'Case finding: Throughout this report this term is applied to that form of screening of which the main object is to detect disease and bring patients to treatment, in contrast to epidemiological surveys.'

The argument that targeting known 'at-risk' groups is case finding, and distinct from screening, is thus not validated by the Wilson and Jungner definitions. The issue is whether people are found by clinicians incidentally in the course of work (heavy smokers) or via a systemic attempt to question the whole population (do you smoke?). Population screening programmes find higher risk groups (women with HPV, men with large aortas) but start to select these groups from the whole population. NHS screening programmes target high risk groups (e.g. men rather than women for aortic aneurysms, women in selected age groups for cervical screening). If the whole population is the starting point, then 'case finding' is another phrase for 'population screening'. It is therefore misleading to suggest that 'case finding' screening groups perceived to be at higher risk, is a different category of screening that can escape normal screening science scrutiny. Notably, a Citizens' Jury in Australia unanimously voted against such 'case finding'.[11]

Misaligned interests

The National Clinical Director for Stroke in England has written

> NHS England does not have a policy to promote screening for Atrial Fibrillation (AF)... However, NHS England does support case finding in high risk populations and opportunistic checks when people present to health services... There is very strong evidence that identifying AF in patients with appropriate CHADSVaSC scores and who are not at very high risk of bleeding is worthwhile so they can benefit from anticoagulation... It is clear that the benefits of anticoagulation greatly outweigh the risks of GI bleeding, subdural bleeding, or any other bleeding complication.[10]

In some areas, 'high risk' has meant age alone, and all over-65s attending the doctor or pharmacy for any reason have been tested; additionally, 'pulse checks' have been promoted to the general population attending sporting events.[12]

However, the UK National Screening Committee position recommends against population screening of atrial fibrillation. A recent systematic review of atrial fibrillation screening concluded 'trials have not assessed whether treatment of screen-detected asymptomatic older adults results in better health outcomes than treatment after detection by usual care or after symptoms develop'.[13] Additionally 'opportunistic checks' cannot replicate the circumstances showing benefit of treating atrial fibrillation in clinical trials. These have

involved patients detected via non-screening routes (e.g. incidental finding during follow up of chronic conditions or symptomatic detection). The risk profile and appetite for diagnosis and treatment of the asymptomatic population cannot be assumed the same as the symptomatic and incidentally found population; thus, the risk to benefit ratio of using anticoagulation cannot be assumed the same. The rise in apixaban and rivaroxaban use comes with concerns of association with increased all-cause mortality compared to warfarin.[14] Additionally, many schemes aimed to increase the diagnosis rate of atrial fibrillation have been sponsored/supported by pharmaceutical and technology companies who stand to gain from increased diagnosis rates. For example, Academic Health Science Networks, who produce 'heat maps' of diagnosis rates and offer 'masterclasses' for primary care staff, work directly with industry and include the aim of 'promoting economic growth, fostering opportunities for industry to work effectively with the NHS'.[15]

Because of the potential for conflict of interest, independent recommendations are required. It is unlikely that patients would be aware of the funding arrangements when offered screening.

'Innovation doesn't need the same standard of evidence'

In Manchester, home to a devolved health administration, lung cancer screening commenced in 2016 with computed tomography scanners in retail centres. People aged between 55 and 74 years with a smoking history and registered at selected practices were offered a 'lung check' as part of the 'Accelerate Co-ordinate Evaluate' NHS England innovation programme. This programme commenced in advance of the final results from the NELSON trial,[16] a European lung cancer screening trial and without cost-effectiveness analysis.

The initiative was subsequently described by Macmillan Cancer as 'highly successful' and an 'extraordinary success' prior to a roll-out in further local areas.[17] It is now embedded in the NHS Long Term Plan.[18]

While there is evidence that screening the high-risk population for lung cancer can delay deaths, the number needed to prevent one lung cancer death is 320 and the number needed to screen to prevent one death overall being 219 over 6.5 years,[19] it also causes overdiagnosis of lung nodules. This programme has had a false-positive rate of 48% in terms of referrals to lung clinics.[20] Issues such as psychological harm, anxiety and general practitioner workload need to be balanced and mitigated. An advertisement for seven consultant radiologists to administer the programme[21] against a background of cuts to smoking cessation services[22] and national shortage of radiologists[23] asks questions of opportunity costs, cost-effectiveness and equity of access, especially given potential for the lengthening of waiting times for symptomatic patients.

Additionally, a screening programme organised without independent evaluation or national co-ordination invites inequality of access, and because no-one is responsible for population coverage, no-one can be held to account for disparities. Further, information enabling informed consent, quality control and audit is normally generated and performed nationally with independent scrutiny. When individual clinical commissioning groups commission and assess their own screening programmes, none of these are assured. Any gap in the evidence base for particular screening programmes should be addressed by undertaking research, with appropriate ethical approval. Effective screening would be welcomed, but programmes of this size and importance require independent arbiters and managed with adherence to clinical aspects, such as predetermined risk, follow-up and nodule management, smoking cessation, high-quality surgery and data to measures process and outcomes.

It is also notable that the offer is not 'cancer screening' but a 'lung health check'.[24] Given the work into producing consistent evidence-based information to promote informed choice, it is uncertain whether these citizens will have received Montgomery standard[25] information. Because only smokers identified by general practitioners are invited, it is not a population screening programme. NHS England have adopted the term 'targeted lung screening'.[26]

However, even screening a smaller population must be evidence-based, equitable and subject to independent assessment evidence to ensure it will do more good than harm at a reasonable cost. NICE make recommendations for tests and treatments of people at high risk of disease but do not have the UK National Screening Committee mandate to prevent programmes to that do not meet effectiveness and cost thresholds, or mechanisms to ensure equitable offers and harm minimisation through data reporting and quality assurance. This 'border territory' needs clear mechanisms of assessing, preventing and running well-evidenced programmes.

Charities: advocates or single issue pressure groups?

Several charities have been involved with advocating, promoting or disseminating information about non-UK National Screening Committee or NICE-approved screening. For example, the Alzheimer's Society promoted dementia screening ('proactive

case finding'),[27] the British Heart Foundation has promoted atrial fibrillation screening ('opportunistic pulse checks')[28] and Macmillan have promoted lung cancer screening.[29]

While working with patients and citizens is vital, single issue groups, no matter how honourable in intention, are biased in favour of detection of one disease. This persists despite flaws in accuracy of testing, opportunity costs and lead time bias – especially problematic when screening is performed outwith randomised controlled trials. Listening to and learning from patients' experience is essential, but independent scrutiny of evidence must lead practice.

Conclusion

In summary, 'case finding' and 'opportunistic testing' have been used as approaches which ignore the Wilson and Jungner criteria and avoid the scrutiny which should be inherent in any type of screening or large programme designed to help high-risk individuals. The UK National Screening Committee and NICE are well positioned to provide this and answer criticisms on the lack of distinctions around the roles of various bodies.[30] It is concerning that industry, single issue charities and individual clinical commissioning groups have worked to commit resources to support screening without independent scrutiny and evaluation.

It is also notable that Ireland, in the light of major problems with their cervical screening programmes, have now committed to an independent National Screening Committee.[27] Yet, when such a committee exists, its expertise must be utilised, and conclusions are accepted, not overwritten or simply ignored. The heart age tool, for example, has not undergone real-world testing, and despite assurances from Public Health England, the potential for low-value consultations as a 'healthy attender effect' are concerning,[31] given complaints of saturation, underfunding, cutting funding for district nursing[32] and increased waiting lists.[33,34] The UK National Screening Committee and NICE exist to defend equity, safety and quality of interventions, and NHS claims for 'case finding' and 'opportunistic testing' should be proactively assessed by them. Further, there is a need to hold to account organisations which promote screening outwith their recommendations. There does not appear to be a mechanism currently in place to do this. Screening is politically popular and attractive to the media and public. But stewardship and sustainability of the NHS require commitment to evidence-based practice, and screening should not be an exception.

Declarations

Competing Interests: In 2014/15 GF participated in 3 Advisory Boards for Bayer Opthalmology. GF's employer was reimbursed for his time. MG has been involved in Live:Lab, a project set up by the pharmaceutical company, AbbVie, to understand the Fear of Finding Out better. https://blogs.bmj.com/bmj/2018/02/01/muir-gray-we-need-to-tacklethe-fear-of-finding-out/. MG has set up and managed screening programmes for 20 years. MM receives income as a GP partner, and for freelance writing, broadcasting and royalties.

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