EARLY TESTING SAVES LIVES.

About this document

This document provides a checklist of actions for engaging local partners in reducing late diagnosis of HIV. It draws on the learning from a pilot project run by MEDFASH with the Greater Manchester Sexual Health Network that brought together key decision-makers, commissioners and providers from the statutory and voluntary sectors to develop and endorse a shared action plan for the delivery of the Halve It campaign goals. It will provide useful guidance to support the development and implementation of plans in other areas to impact on this important public health outcome. The full report is available at www.medfash.org.uk and www.halveit.org.uk.

Halving late diagnosis of HIV: a toolkit for local action

Halve It is a coalition of national experts working with all levels of government and the NHS to reduce the proportion of people undiagnosed and diagnosed late with HIV through public policy reform and implementation of good practice.

Public Health England estimates that at the end of 2012, 98,400 people were living with HIV in the UK, of whom 22% remained undiagnosed and were therefore unaware of their infection.

If diagnosed early, HIV can be successfully treated and people with HIV can anticipate normal life expectancies. Late diagnosis, in contrast, is associated with a greater risk of hospitalisation and HIV-related illness, reduced life expectancy, and increased health and social care costs. It is also associated with increased onward transmission and continued sexual risk-taking while people are unaware of their HIV-positive status.

From a 2010 baseline, our goals are to:

- Halve the proportion of people diagnosed late with HIV (CD4 count <350mm$^3$) by 2015
- Halve the proportion of people living with undiagnosed HIV by 2015

Authors

Dr Mark Limmer Division of Health Research, Lancaster University
Ruth Lowbury Chief Executive, MEDFASH


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Registered office: BMA House, Tavistock Square, London, WC1H 9IP
Tel: +44 (0) 207 383 6345. Email: enquiries@medfash.bma.org.uk. Web: www.medfash.org.uk
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*Observer members
How to develop local engagement and agree actions

Local structures, contexts and resources will mean that the process of bringing together stakeholders to develop and endorse an agreed plan of action may vary from place to place. The diagram below sets out the key stages that are likely to be common to all areas and can be adapted to local needs. The process is set out in a linear fashion, with one activity following another. In reality, it is likely to be less clear-cut than this, with some activities being returned to on a number of occasions.

1. Driving the local engagement process. Establishing who is going to lead and drive the process. Strong, credible leadership through the local Director of Public Health or equivalent supported by committed individuals from key stakeholder groups.

2. Assessing the local situation. Using existing statistical and ‘soft’ data, supplemented by the research literature and national guidance, to clarify the local context, identify target communities and assess the local resources available.

3. Identifying barriers and enablers. Consulting with key stakeholders and members of target communities to identify factors that enable and inhibit testing locally. Focusing on what is currently effective and building on it is as important as addressing barriers.

4. Defining priority actions and developing the outline plan. Using the national and local data alongside the findings of the consultation to draw together an outline plan that can be presented, built on and endorsed at the local engagement meeting.

5. Identifying and engaging the key stakeholders. Who needs to be involved in the local engagement meeting? Who can impact on defining and delivering the action plan? Thinking beyond those currently involved is important – new interventions will probably require new partners.

6. Local engagement meeting. The opportunity to bring together the key stakeholders to develop the outline plan into an agreed and endorsed action plan with clear activities and responsibilities assigned to and accepted by participants.

7. Action plan, accountability and leadership. With the action plan agreed, the final step is for it to be endorsed by senior leaders with clear lines of accountability and agreed mechanisms for monitoring progress.

Key learning points

The project in Greater Manchester provided some key learning points to support local engagement in planning to address the Halve It goals.

- The key challenge may be less a matter of hearts and minds and more about practical implementation. The experience with Greater Manchester was that most individuals and agencies did not need to be persuaded of the need for early diagnosis, but were struggling with the process of implementation. However, there was the need for awareness-raising for partners in local authorities, some of whom had only recently taken on responsibilities in relation to HIV.

- Delivered locally, Halve It is not just a campaign but a programme of embedded work. The use of the word ‘campaign’ carries with it a short-term, intensive connotation but at a local level the need was for sustained, embedded interventions.

- Activities and priorities must reflect the local need, resources and infrastructure. Collecting local intelligence on both the nature of the need and the resources that can be utilised to address it is an important first step in developing a local action plan.

- HIV is one priority among many for services in the midst of change, uncertainty and vulnerability. The reality of this need to be recognised but it should not be a cause of inertia – the nature of the public sector is such that this will always be the case to some degree.

- Leadership and accountability are important. Identifying who is taking a lead in the development and implementation of the interventions and how they are going to be held accountable for progress is a key facet of driving the work forward.

- Financial savings may not be the main motivating force. While the financial arguments are compelling, the experience within Greater Manchester is that they are not the main drivers and focusing on this aspect of the justification of Halve It at the expense of the public health benefits may be counterproductive.

- It is important to identify the quick wins that need to run alongside the sustained impact. Building confidence in the ability of the planned interventions to make an impact is enhanced by some early evidence of success, which also serves to maintain momentum and enthusiasm.

- Universal versus targeted approaches to testing – there is a need for both but the latter may deliver the quicker wins. More immediate impact on the rates of early diagnosis is likely to be delivered by targeted interventions with high prevalence communities, but the embedded normalisation of HIV testing across the population is also important and may take longer to bring about.

Conclusion

The case for the importance of the early diagnosis of HIV is compelling, with clear health, social and financial benefits for individuals and for society as a whole. The complexity of achieving higher rates of early diagnosis requires that agencies across the statutory and voluntary sectors work together to promote more flexible ways to access testing, targeted at those most at risk of HIV and making best use of scarce resources. The experience from this project in Greater Manchester is that there is an appetite for cooperation and innovation to address the Halve It goals and that effective engagement with key stakeholders lays the foundation for successful and sustained implementation.