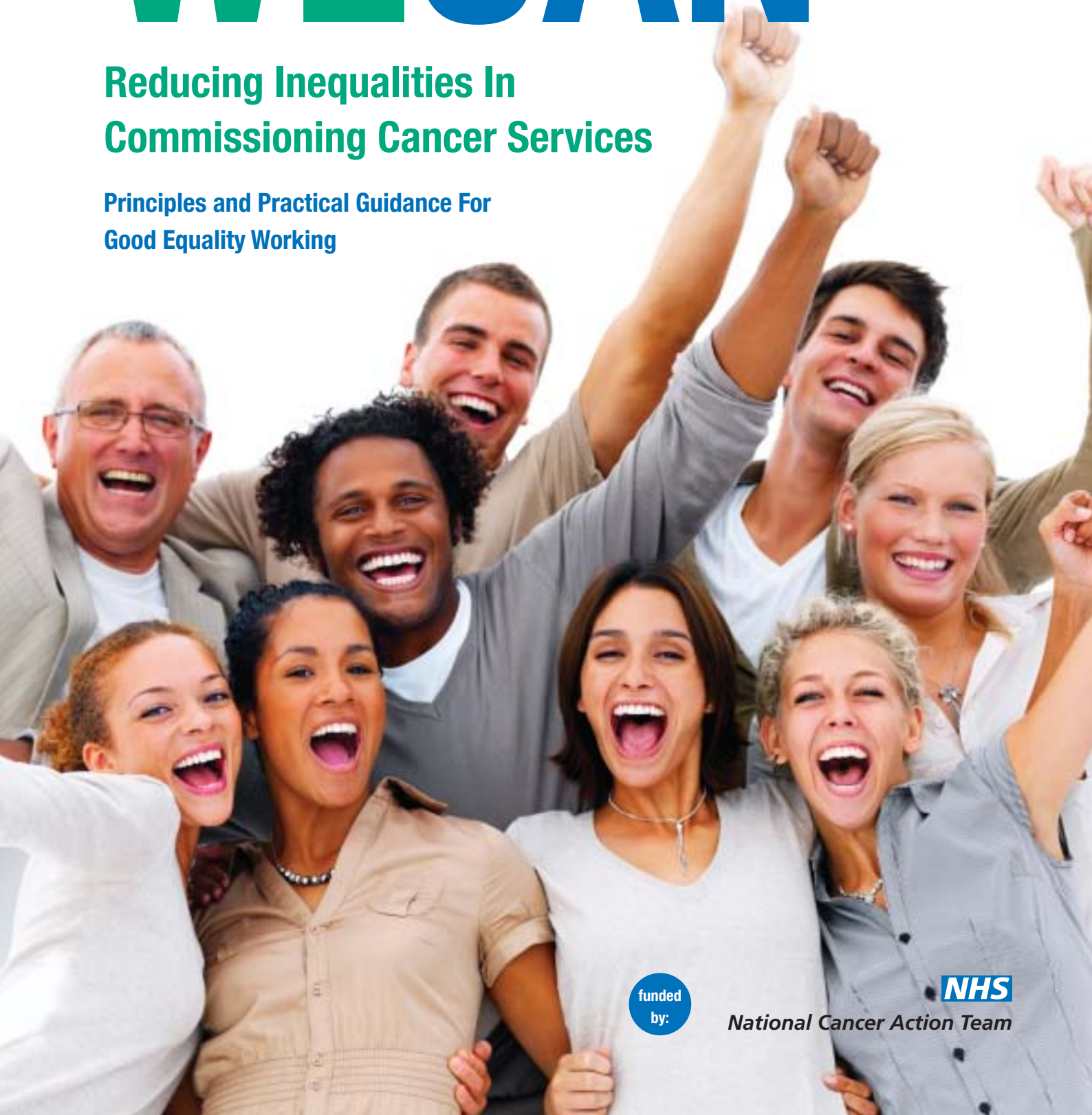
NHS

NATIONAL CANCER EQUALITY INITIATIVE (NCEI)

# WECAN

## Reducing Inequalities In Commissioning Cancer Services

### Principles and Practical Guidance For Good Equality Working



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# Foreword

One of the key aims of the Cancer Reform Strategy was to reduce inequalities in cancer incidence and increase access to high quality cancer care and cancer outcomes. The Cancer Reform Strategy was subject to an Equality Impact Assessment which showed that there would be no overall adverse effect on inequalities as a result of the measures for cancer that the strategy proposed. However, we wanted the strategy to go much further than that, achieving a substantial reduction in inequalities in cancer.

We began the National Cancer Equality Initiative (NCEI), bringing together key stakeholders from the professions, voluntary sector, academia and equality groups to develop research proposals on cancer inequalities, test interventions and advise on the development of wider policy.

The NCEI advisory group was established in 2008. Its first major action of the NCEI was to create a matrix to send to the cancer community in an attempt to gather examples of good practice in reducing inequalities in cancer care. Those examples are used as the case studies to accompany the principles and guidance set out in this report.

Rather than setting up workstreams and duplicating work, NCEI has charged other CRS initiatives with embedding equality issues within their work programmes. These initiatives are: National Awareness and Early Diagnosis Initiative (NAEDI); National Cancer Survivorship Initiative (NCSI); National Cancer Intelligence Network (NCIN); Cancer Patient Experience Survey Programme (CPESP). NCEI champions are being established on all the steering groups driving forward these initiatives.

Inequalities may be experienced by a range of different groups within society. These include:

- Socio-economically deprived groups;
- Black and minority ethnic groups;
- Older or younger people;
- Men or women;
- People with disabilities;
- People from particular religions or with particular beliefs; and
- Gay, lesbian or bisexual people.

There are multiple potential sources of inequality relating to cancer, which can impact on incidence, survival, mortality, patient experience or quality of life. These include:

- Awareness and attitude to lifestyle risk factors for cancer;
- Awareness of the early signs and symptoms of cancer;
- Uptake of prevention, screening and primary care services;
- Access to diagnostic and treatment services from primary care;
- Provision of information and support;
- Exposure to infections linked to cancer; and
- Genetic risk of developing cancer.

The NCEI provides a focus for accessing information about good practice and applying learning from a range of equalities initiatives. Good working relationships have been established with DH Equality and Human Rights colleagues. Macmillan Cancer Support has agreed that their human rights programme of work Know Your Rights, will be jointly NCEI badged, and appropriate links and joint working are being identified.

Cancer, particularly screening, has been identified as a priority in the second wave of the DH Pacesetters programme. Development areas identified include breast screening in the over 70s, breast screening in BME women, cervical screening for lesbians, testicular cancer awareness in young men, screening for trans-men and trans-women, and palliative care for cancer patients from faith groups.

We believe that in these and other ways, equalities work is very much part of the current health agenda. It will undoubtedly help in the delivery of Quality Innovation Productivity and Prevention (QIPP)

Much good work has gone on in the NHS to help to reduce inequalities in cancer care. However, many of the developments undertaken to date have proved to have little impact or, where there was clear impact, were not replicable in other settings. This is for a number of reasons, including lack of robust planning, lack of focus and lack of evaluation. This report aims to be an enabling document to help commissioners and providers to plan, deliver sustain and share good practice in equality developments. It should be read in conjunction to other major policy initiatives: World Class Commissioning, Transforming Community Services and the Cancer Commissioning Guidance and Tool Kit (see links under Further Information).

We hope you find it useful as you take forward your local plans to reduce inequalities in cancer services.

**PROFESSOR MIKE RICHARDS/JOANNE RULE (CO-CHAIRS, NCEI)**

# Introduction

**Across the public sector, there is now a recognition that equality of outcomes and personalised services will only be delivered by working with communities, recognising difference and tailoring provision rather than a 'one size fits all' approach. Furthermore, when people find themselves in need of care they can be at their most vulnerable. It is therefore vital that those who commission and provide services proactively ensure that people's individual needs, their dignity and their human rights are respected at every stage of the care journey. This is what it means to take equality, diversity and human rights seriously.**

**Department of Health Single Equality Scheme, June 2009**

This document is intended for those in PCTs, SHAs, cancer networks, and the voluntary sector organisations, who are commissioning or running services that aim to reduce cancer inequalities. It can be used both as a tool and as guidance. For primary care or acute service commissioners it can be used as a checklist for equalities proposals or tenders, allowing you to ensure that potential services include the suggested criteria for success. It should be read in conjunction to other major policy initiatives: World Class Commissioning, Transforming Community Services and the Cancer Commissioning Guidance and Tool Kit (see links under Further Information).

Reducing inequalities in the provision of cancer services and the experience of cancer patients is the right thing to do, but also bound in legislation. All public authorities, including the Department of Health and the NHS, are bound by the statutory equality duties. These are set out in section 76A and B of the Sex Discrimination Act 1975, section 71 of the Race Relations Act 1976, and section 49A and D of the Disability Discrimination Act 2005.

In addition, the Equality Act (Sexual Orientation) Regulations 2007 prohibit discrimination on grounds of sexual orientation in the provision of goods, facilities or services; part 2 of the Equality Act 2006 prohibits discrimination on grounds of religion or belief in the provision of goods, facilities or services; and the Employment Equality (Age) Regulations 2006 prohibit discrimination, harassment and victimisation in employment and vocational training on the grounds of age.

These obligations set out in legislation are soon to be streamlined and extended by the Equality Bill now making its way through Parliament, which will provide a helpful framework for making a reality of the commitment to reduce inequalities.

# Key Principles and Practical Guidance for Good Equality Working

## 1. You have an evidence base

- Interventions to reduce inequalities in cancer services should be undertaken where there is clear local evidence that an inequality exists.
- This evidence could come from: local equality impact assessments; local health equity audits; quantitative and qualitative local intelligence, usually included in the joint strategic needs assessment; the views of local people.
- Anecdotal evidence of inequalities should be confirmed by further investigation.
- Process mapping of the appropriate patient pathways, including primary care, will enable identification of key areas where interventions may make a difference.
- PCTs, Cancer Networks and Cancer Registries are a good source of local data and evidence, as is the Cancer Commissioning Tool Kit. NHS Evidence may also be helpful.
- You should ask yourself – "Is this information good enough for the decision I have to take?"
- The National Support Team (NST) for Health Inequalities was set up in 2007 to provide support to local areas focusing principally on the life expectancy element of the 2010 Public Service Agreement (PSA) target – to reduce by at least 10% the gap between the fifth of areas with the worst health and deprivation indicators (Spearhead areas) and the population as a whole. In 2008 they published "Systematically addressing Health Inequalities" which you may find useful in planning your work.

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_086570

- The National Awareness and Early Detection Initiative (NAEDI) has developed Local Awareness and Early Diagnosis Baseline Assessments: A Guide for Cancer Networks and PCTs, which may also be useful when considering inequalities:

http://www.ncin.org.uk/outcomes/naedi_baselining.shtml

## Early Diagnosis Lung Cancer - Doncaster PCT

Doncaster PCT reviewed the evidence they had on their own population and identified that there was a high incidence of cancer (they compared their rates to national rates) and this, coupled with low intervention rates, was leading to poorer survival rates. Local clinicians believed that people were presenting 'late' with 'end stage' disease and thought that simple diagnostics, such as chest x-rays, carried out earlier in the patients' journey, could address this. Their assumptions regarding late presentation and stage of disease were then validated using the LUCADA database and an audit of GP referrals for chest x-rays and interviews with local people to understand any barriers to presentation. This solid evidence base provided Doncaster PCT with a good understanding of the problem ans so allowed them to act accordingly to increase the number of chest x-rays in symptomatic patients at an earlier stage.

**Contact: Rupert Suckling, Doncaster PCT, www.doncasterpct.nhs.uk**

## African & Caribbean Information Day - Breast Cancer Care

Breast Cancer Care (BCC) drew upon a range of sources to provide an excellent evidence base for their project. They considered the anecdotal evidence around the information needs of the African & Caribbean community in addition to academic literature which highlighted the high incidence of breast cancer in BME women and the significantly poorer outcomes experienced by this group. BCC then pulled this together with their own research which highlighted a real need for culturally sensitive information to be made available for BME people with breast cancer and planned and ran a successful Information Day for African & Caribbean people in London and the South East region.

**Contact: Roisin Furlong/Phyllis Steadman on 0845 077 1895**
**www.breastcancercare.org.uk**

## 2. Work is targeted and specific

- Think about what you are trying to achieve and whether you need a tailored approach.
- What issue are you addressing? Who does it affect – the whole community or a particular group within it? Which communities are you trying to reach and why? Do you know the relevant facts and figures about your audience? Where does your audience live (eg are they found in one particular part of your area)?
- Be clear about your message or the service change needed.
- Some PCTs have experience of understanding parts of their community through social marketing developments.
- Consider alternative formats such as audio and DVD, and use of specialist media (eg ethnic media).
- Some developments may benefit from targeting more than one audience.
- Each region has a regional lead from the DH funded National Social Marketing Centre (NSMC). They can help with training and procurement of social marketing. The website clearly explains social marketing, with a number of case studies.

http://www.nsmcentre.org.uk/

## The Cancer Awareness Roadshow (Cancer Research-UK)

Cancer Research UK's Mobile Cancer Awareness Roadshow aims to play a vital role in providing health information to people that need it, especially those living in low income communities. It consists of three Mobile Cancer Awareness units that are staffed by health information nurses and stocked with a range of cancer prevention and early detection information. Whilst on board visitors can talk to a Roadshow nurse, take a smokerlyzer test, have their Body Mass Index measured and find out about local health promotion services. The Roadshow has welcomed over 81,000 visitors since April 2006 from towns and cities all across the UK.

### Targeting

The units specifically target communities where cancer incidence is high but knowledge of preventable risk factors for cancer is thought to be low. The units specifically target socio-economically disadvantaged areas. A stringent location choosing process is used. By using tools such as Mosaic, Experian and Health Acorn, and information sources such as the Indices of Multiple Deprivation, areas are pinpointed where the project is likely to impact on the target audience and attract a reasonable number of visitors.

The design of the Mobile Cancer Awareness Units has been chosen to create an accessible and welcoming space to encourage our target audience to step on board and overcome discomfort when talking about cancer. We employ a range of formats to communicate our key messages and information can be accessed via our leaflets, watching DVDs on board, and speaking to nurses and specially trained staff.

Independent evaluation has considered the impact of the project on visitors, their awareness of key messages and their intention to change behaviour. In addition to independent evaluation, feedback from visitors is monitored year round through questionnaires and analysis of nurse feedback. Each year these results are utilised to inform the annual plan for the next year.

**Contact: cancerawarenessroadshow@cancer.org.uk**
**www.cancerresearchuk.org/healthyliving/cancerawareness roadshow/**

## 3. There is community engagement

**Proactively seek and build continuous and meaningful engagement with the public and patients, to shape services and improve health.**

**(World Class Commissioning: competencies, December 2007 – see link in Further Information)**

- A patient centred approach is essential. Community engagement takes as its starting point the premise that the community itself has the greatest ability to access its own members in order to raise awareness and assess need, and that agencies have the responsibility to develop services to meet that need[1].
- Engagement is the involvement of the public in policy and service decisions which affect them. The three main stages of development are: information gathering (eg surveys of pubic attitudes); consultation (eg focus groups); and participation (eg community forums).
- The benefits of involving the community in partnerships are: better decision making; more effective service delivery; greater community support; and community development.
- A strategic approach should be taken. In developing a strategy: which communities are to be targeted? Which methods of engagement are to be used? (And communities themselves should be involved in deciding engagement methods). What decisions will be informed as part of the engagement activities? What mechanisms will be in place to enable ongoing community input to the decision-making process? What forum/mechanisms will make the decisions? What are the timescales? How will decisions/ outcomes be communicated? And how will you ensure affective feedback throughout the process?
- There should be ongoing dialogue with communities throughout the lifetime of a development, and beyond where appropriate.

### The Healthy Communities Collaborative

was set up by the Improvement Foundation with the support of the Health Development Agency in 2002. It aims are to:

1. Address health inequalities in areas of socio-economic disadvantage
2. Be the catalyst enabling communities and agencies to work together for common goals
3. Harness the skills and knowledge in communities and make them work to reduce inequalities
4. Recognise and change poorly functioning systems using rapid improvement techniques.

The Healthy Communities Collaborative involves 19 sites across the country working to raise awareness of the signs and symptoms of common cancers and to encourage people who may have symptoms to seek help earlier.

The sites are in areas of high deprivation and are all Spearhead Areas.

Using social marketing techniques, each site undertakes their own unique targeted interventions – developed by the team of health professionals and volunteers.

The interventions have engaged people through a range of activities in a range of settings. These include snakes & ladders, quizzes, hand massages, in bingo halls, post offices, mosques, amusement arcades . . .The projects are working with many communities including black and ethnic minority groups and travelling communities.

The projects target different groups at particular risk of late cancer diagnosis; early results are promising, and feedback from participants has been very positive. Monitoring and evaluation outcomes are being tested.

**Contact: Teresa.Karran@improvementfoundation.org**

[1]A dialogue of equals: The pacesetters programme Community Engagement Guide, Department of Health 2007

## Cancer Translation Project for London & Hertfordshire - Macmillan Cancer Support

The project steering group included community representatives. In addition, advisory groups were established to provide a forum where all community representatives could meet. The project itself included the recruitment of a Community Project Manager, whose remit was to build relationships with all community groups to secure their understanding of, and participation in, the project.

Engagement with the community at all levels enabled this project to really understand the needs of the community and provide translated materials that met these needs.

The advisory group for the project consisted of project workers, healthcare professionals, members of different community groups, and also people working in different communities to deliver health advice and advocacy. This group looked at all booklets for all languages and advised on booklet content whilst also considering how best to promote the information.

The Community Project Manager knew many of the community groups from previous work, but also did lots of research and groundwork to seek out newer community groups with which to engage. She did this mainly by using the internet, for example council websites, and talking to her contacts. She then went to speak to the new groups and built up relationships with them.

We aimed to get a representative from each of the target community groups to sit on the advisory group, and then to help to establish a focus group for each community to talk in much more detail about the language and content of each of the booklets designed for that community. Some of the groups we worked with in this way were the Iraqi Community Association, Lambeth Chinese Association, Stockwell Partnership (Portuguese, French and Spanish communities) and Derman (a Turkish organisation based in Hackney).

Once people had joined the advisory group, project workers would give a presentation to them about the project and its aims. However, when the Community Project Manager went out to talk to different community group meetings, this was done much more informally. As a way of thanking the groups for participating, the Community Project Manager gave cancer awareness talks to the groups after the booklets were completed.

> **Community engagement is vital for this project as the authenticity of the languages, content and layout has to be taken into consideration. It also gives the project worker the opportunity to advise and promote mainstream cancer organisations and their services, which most of the targeted communities are still unaware of.**

**Contact: Rebecca Leadley, Macmillan**
**rleadley@macmillan.org.uk**
**http://www.macmillan.org.uk/**

## 4. There is service improvement and innovation

- Improvement ideas can come from service providers and service users alike, often working in partnership.
- Small focused changes can be effective using Plan, Do, Study, Act (PDSA) cycles (see principle 5) .
- Use appropriate published guides, such as Thinking Differently (NHS Institute for Innovation and Improvement):

http://www.institute.nhs.uk/building_capability/new_model_for_transforming_the_nhs/thinking_differently_guide.html

- The *Thinking Differently* book will provide you with a range of practical approaches and tools that many NHS leaders and front-line teams have already used to fundamentally rethink pathways of care and service delivery. This guide will not only help you to learn how to improve the services you provide, but how to transform them.

> **"We need to have imagination and courage in order to seize the opportunities there are to transform the provision of care in the NHS."**
>
> **(David Nicholson, Chief Executive, NHS England)**

- When teams have identified ideas, it will be important to decide which are worth testing immediately, which require further thought and which should be considered in future strategic planning.
- It is important to check where possible that the service improvement ideas you come up with have not been used before and found to be ineffective.

### De Botty Business - The Prostate Cancer Charity

The Prostate Cancer Charity (TPCC) commissioned poet Benjamin Zephaniah to write an educational studio piece to communicate health promotion messages, around prostate cancer health. TPCC understood that theatre is widely considered as an excellent educational tool with which to explore taboo issues and generate debate. It was felt that by taking the issue of prostate cancer into a theatrical arena, the content of the play would reach the hearts and minds of the individuals affected in a way that reading a pamphlet or listening to a speech would not.

The innovative use of theatre and comedy to raise awareness of prostate cancer in a community setting, was a success and a workshop was held to disseminate the main findings to community based health workers.

**Contact: Lindsey Bennister, The Prostate Cancer Charity, Lindsey.bennister@prostate-cancer.org.uk http://www.prostate-cancer.org.uk**

## 5. Interventions are tested and refined

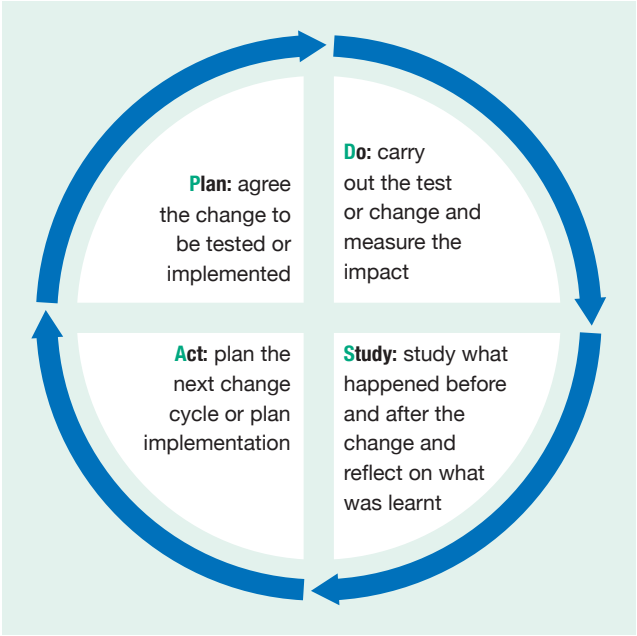
- Good change ideas are rarely effective without refinement following testing – this is where the PDSA cycle should be used on your ideas:

**Plan:** agree the change to be tested or implemented

**Do:** carry out the test or change and measure the impact

**Study:** study what happened before and after the change and reflect on what was learnt

**Act:** plan the next change cycle or plan implementation




- By learning from each cycle and making changes in a structured and incremental way, a new idea can be implemented with more chance of success.
- PDSAs build on each other; it may take several PDSA cycles to get an implemented improvement; PDSAs can produce spin-offs (improvements in other areas not originally envisaged); and all improvements involved change but not all changes are improvements[2].
- More information on PDSA cycles can be found in the Improvement Leaders' Guide (see Further Information).
- By refining your project, you will avoid wasting money and may save money downstream.

### What has worked elsewhere

A recent report to the UK National Screening Committee on reducing inequalities in screening programmes[3] discusses interventions which do and do not work based on a literature review. Interventions which actively engage the target audience were more likely to succeed than reminder letters. These included in-person education and telephone calls to patients. Practical help with booking and attending screening appointments (eg through patient navigators) was also generally helpful. Combinations of interventions were usually more successful than single interventions. The added benefit of tailoring letters and phone calls culturally or by risk was not clear, and in some cases gave worse outcomes.

### The Health Promotion Programme to Increase Bowel Cancer

Screening Uptake project carried out by Derbyshire PCT was based on evidence from findings in two pilot studies. These pilot studies justified the health promotion approaches considered and the groups of people targeted.

**Contact: http://www.derbyshirecountypct.nhs.uk/**

### GET CHECKED Early Presentation of Cancer Symptoms

Halton and St. Helen's PCT were involved in the first pilot of the Healthy Communities Collaborative (HCC) Cancer Programme. The successful piloting of wave one of the HCC enabled the PCT to move forward with their project, "Get Checked".

The learning from testing new approaches is now being used opportunistically by other health professionals, such as podiatrists. This work is part of the PCT's overall programme of work to reduce health inequalities.

**Contact: Teresa Karran, The Improvement Foundation, teresa.karran@improvementfoundation.org**

[2]Improvement Leaders' Guide 1.2: Process mapping, analysis and redesign, NHS Modernisation Agency 2005

[3]Interventions to reduce inequity and inequality in accessing national screening programmes, A report for the UK National Screening Committee, October 2008

## 6. You are able to measure effectiveness

- Measures are essential for evaluating your improvements (see principle 8). How will you know that your intervention has worked? Measures are needed to establish a firm baseline; assess change and to ensure progress is monitored. Measurement needs to take place frequently and continued once a change has been made to monitor performance over time.
- Measures should be kept simple so they speed improvement up, not slow it down.
- Measures should be easy to collect and reliable, and from existing data wherever possible, with the service users' interests represented.
- Select the most appropriate way to present your data (eg run charts, funnel plots, statistical process control charts).
- Ensure those collecting the data see the outcome of the data collection process.
- The Cancer Commissioning Toolkit may be a good source of data in developing your measures (see link in Further Information).
- New tools are being tested and used which may be useful, for example the Cancer Awareness Measure and the Primary Care Cancer Audit.
- Measures should explicitly include information on categories of disadvantage or exclusion (eg ethnic group, disability, sexual orientation) to see whether inequalities based on these factors are reduced.

### Early Diagnosis Lung Cancer - Doncaster PCT

This project aimed to address the problem of late presentation of lung cancer in Doncaster. A campaign was run, that targeted men aged 50-60 who were current or ex-smokers (and their families) from the most deprived parts of Doncaster.

The aim of this project to change behaviour was measured in three ways, a change in stated behaviour (increase awareness by 5% in target audience), a change in x-ray referral rates (by 20% in target GP practices) and a change in the stage of presentation for people with newly diagnosed cancers (from 11% to 19% stage I or II). Two of the three measures are routinely available.

**Contact: Rupert Suckling, Doncaster PCT**
**www.doncasterpct.nhs.uk**

### Open up to Mouth Cancer - Cancer Research UK

Cancer Research UK carried out an awareness survey before their project, which provided a baseline with which to compare results from after the pilot. This allowed one simple and effective way of measuring the success of the intervention.

One of the project's success measures was to raise awareness of oral cancer symptoms and risks, including smoking, chewing tobacco and chewing betel quid with or without tobacco.

Cancer Research UK found there was a significant improvement in awareness of key symptoms and risk factors for mouth cancer.

In order to measure this, Cancer Research UK carried out awareness surveys before, during and after the pilot. Measuring the baseline levels of awareness provided a simple and effective way to assess the impact of the intervention against the defined success criteria, and allowed them to measure how the impact was sustained over time. Cancer Research UK found there was a significant improvement in awareness of key symptoms and risk factors for mouth cancer.

**Contact: Hazel Nunn, Cancer Research UK, 0207 061 8370**
**www.cancerresearchuk.org/healthyliving/openuptomouthcancer/**

## 7. You have champions and work in partnerships with others

- Champions are important in communicating the message of what you are trying to achieve, and can influence others. Leading opinion formers should be identified and targeted.
- Champions can come from various groups: communities themselves, local services or your own organisation.
- Influential sponsors in your organisation can also help drive the change idea. Some will already have formal leadership roles, but others with support and administrative roles may also provide informal leadership.
- The rationale for change should be sold to key opinion leaders so they can support you.
- Understanding those who might resist change is also important.
- Partnership working will not only allow you to get a broader range of views, it can also generate improvements to your ideas and gain "buy-in" to increase your chances of success.
- Groups to consider in partnership working can be from the voluntary sector (eg charities), the statutory sector (eg Local Authorities) or community groups (eg football supporters clubs).
- Partnership working should be continuous, not just something you do at the start of your improvement work.

### Cancer Translation Project for London & Hertfordshire – Macmillan Cancer Support

The project was established to produce three Macmillan Cancer Support leaflets and a combined audio version which aimed to meet the information needs of people affected by lung cancer diagnosed within the five London cancer networks. The information was produced for people speaking 13 different languages. This project was a good example of partnership working. Macmillan, the Afiya Trust, the North East London Cancer Network and the North London Cancer Network worked together and they also got the Roy Castle Lung Foundation and voluntary groups on board in the role of "critical friends". The project was overseen by a steering group, which includes information specialists, nurses, service development, BME community advisers and so on, demonstrating great partnership working across a variety of fields.

**Contact: Rebecca Leadley, Macmillan**
**rleadley@macmillan.org.uk**
**http://www.macmillan.org.uk/**

### African Caribbean Awareness Project - The Prostate Cancer Charity

The Prostate Cancer Charity (TPCC) set up an awareness raising project across five regions in England. The unique nature of this project was that it was undertaken in partnership with voluntary, statutory and community organisations, allowing a broad scope of influence and development from healthcare worker and community groups. Throughout the project the partnership organisations were given the opportunity to provide feedback which ensured the project was on track and taking into account the views of the partner organisations.

For example, in Bradford, the advisory group consisted of representatives from the Dominican Association (a faith group), Health of Men (men's health project), Federation of African Caribbean Elders Ltd (community group), and Bradford and Airedale Primary Care Trusts. Members of the group came from a variety of professional backgrounds and included a Health Promotion Development Officer, a Men's Health Adviser, a Patient and Public Involvement Lead, a Cancer Development Worker and an Outreach Co-ordinator

Partnership working with a variety of stakeholder groups was vital in achieving success. Partners provided local expertise and contacts, including local celebrities, media, and made personal approaches to other local groups and organisations. The Prostate Cancer Charity provided expert help and guidance, co-ordinating the partnership and providing expertise in prostate cancer, backed up by information resources. Evaluation of the project showed that advisory groups welcomed the guidance from an independent 'expert' organisation and viewed this as essential to co-ordinate the diverse community groups and provide clear leadership and resources.

**Contact: Lindsey Bennister, The Prostate Cancer Charity,**
**Lindsey.bennister@prostate-cancer.org.uk**
**www.prostate-cancer.org.uk**

## 8. You evaluate your work

- Evaluation needs to be built in at the outset of any change management programme.
- Establishing effective measurement (see principle 6) will make evaluation easier.
- Data should be collected on quantitative activity as well as qualitative information on the experience of using and providing services.
- Activity and experiences should be monitored over time to map changes to services after change ideas have been implemented.
- Good evaluation is essential if you are to demonstrate that your development is successful, can be sustained and is replicable in other settings.
- It is important that evaluation helps others to emulate your successes to spread good practice, avoid potential pitfalls and improve services more quickly.
- Results should be published in an accessible format.

### African Caribbean Awareness Project – The Prostate Cancer Charity

The Prostate Cancer Charity undertook an evaluation of their project by asking for feedback from participants and partner organisations in addition to reviewing the success criteria against baseline data. An independent evaluation process was carried out which included surveys and questionnaires.

**Contact: Lindsey Bennister, The Prostate Cancer Charity,**
**Lindsey.bennister@prostate-cancer.org.uk**
**www.prostate-cancer.org.uk**

### Cancer Translation Project for London & Hertfordshire – Macmillan Cancer Support

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An in-depth evaluation process was set up and was run in each seven month cycle of the project. The evaluation was carried out in a variety of ways, with the use of focus groups and survey and collaborative working with the Lung CNS support groups.

"Projects really benefit from well thought out evaluation questions from the beginning. This gives a focus to what you are trying to learn and enables the most appropriate data to be collected –including peoples reflections at the time. The lung cancer project evaluation (which worked with Macmillan, the Afiya Trust and Cancer Equality) has enabled us to look at both how the project worked and the impact of the material it produced. This will not only help assess the project's success but will also enable the sharing of lessons learnt with others"

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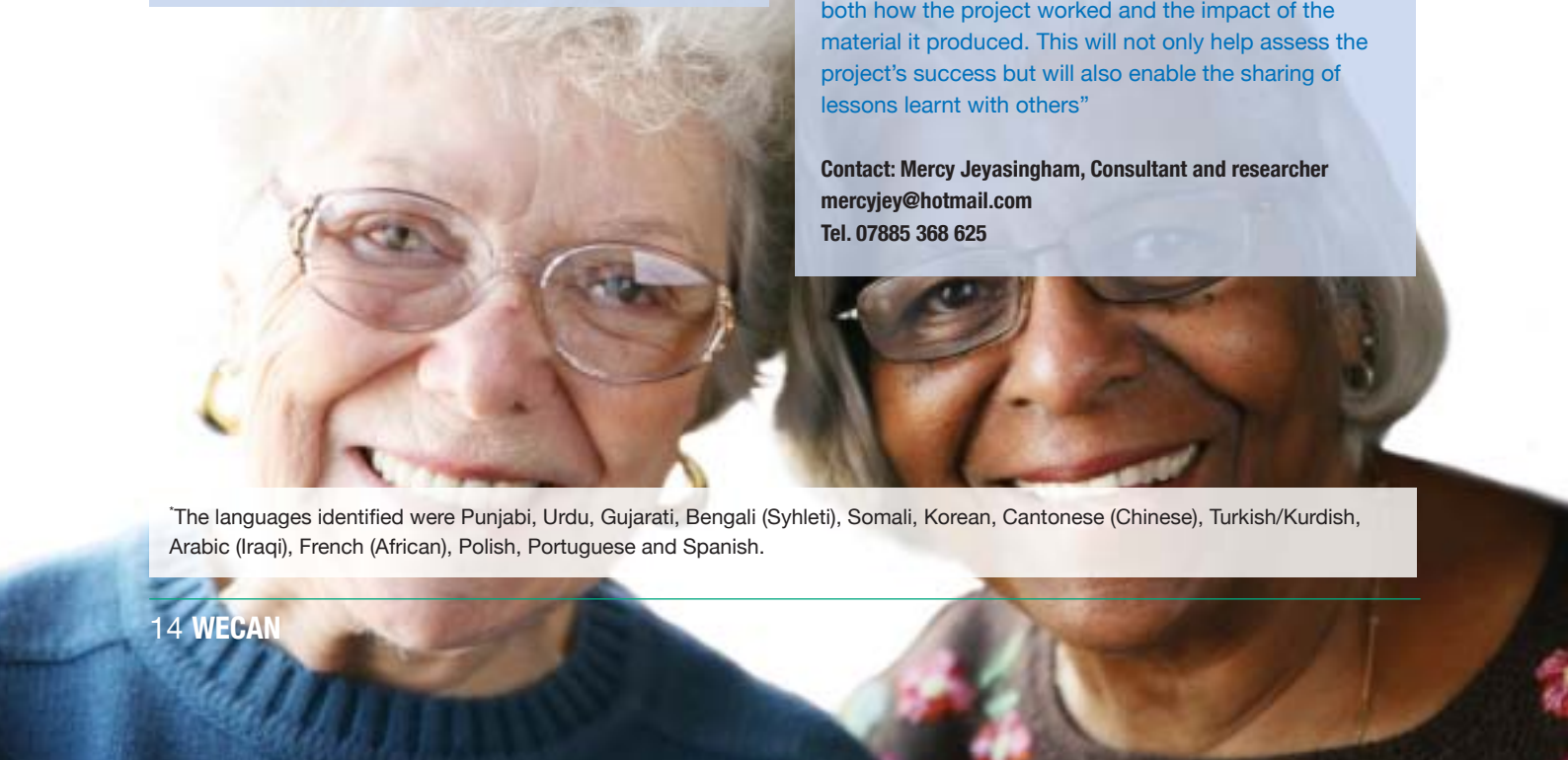

*The languages identified were Punjabi, Urdu, Gujarati, Bengali (Syhleti), Somali, Korean, Cantonese (Chinese), Turkish/Kurdish, Arabic (Iraqi), French (African), Polish, Portuguese and Spanish.

## 9. Sustainability is built-in

- If a change is successful, it should become the norm and things should not be allowed to drift back to the way they were.
- The NHS Sustainability Model and Guide[4] identifies 10 factors relating to process, staff and organisational change. These are:
  - Benefits beyond helping patients
  - Credibility of evidence
  - Adaptability of the improved process
  - Effectiveness of the system to monitor process
  - Staff involvement and training to sustain the process
  - Staff behaviours toward sustaining change
  - Senior leadership engagement
  - Clinical leadership engagement
  - Fit with the organisation's strategic aims and culture
  - Infrastructure for sustainability
- Spread of good change ideas is more likely to happen where the new practice has: relative advantage; low complexity; compatibility; trialability; observability; and capacity for reinvention.
- Sustaining and then spreading improvement is a fundamental element of service improvement.
- Some innovations will be transferable given certain conditions while others will need to be modified to suit the local context.
- Most service development or change to address socio economic inequalities will need to include partnership working to address the wider determinants of heath.

### The Prostate Cancer Charity (TPCC)

received funding for three years from the Department of Health to run the African Caribbean Awareness project. Once this funding came to an end, TPCC incorporated the work into their new strategic approach and identified it as one of their key goals.

The charity realised how important this piece of work was and the evaluation showed how beneficial the project was, so TPCC included it in their new long-term strategic approach. The charity now continues to fund this project with core funding but has been able to raise additional funds from other sources eg City Bridge Trust to support the work.

TPCC recognised that the African Caribbean community were a high risk group. The project had benefited from three years funding, which really kick started the work. The evaluation showed there was a strong evidence base showing what they were doing was making an impact but also showed them where they could improve.

The robust evaluation and evidence base also gave the project credibility and the opportunity to apply for further funding.

### Early Diagnosis Lung Cancer - Doncaster PCT

This project used social marketing principles to address the problem of late presentation of lung cancer. The project targeted men aged 50 – 60 who were current or ex-smokers in the most deprived parts of Doncaster. Doncaster PCT identified this project as a part of delivering "Reducing Inequalities: Achieving Early Impact Programme" and so will continue beyond initial funding

**www.doncasterpct.nhs.uk**

[4]www.institute.nhs.uk/sustainability, NHS Institution for Innovation and Improvement

## 10. Learning is shared

- The NCEI will provide a repository for spreading good practice from successful developments. This will be through the NCEI Newsletter and the dedicated website: www.cancerinfo.nhs.uk
- Consider spreading your work locally. Your cancer network would be a good place to start.
- Consider writing a paper for a peer reviewed journal. Growing the evidence base for good equality developments is essential.
- Identify places to present your development and results, whether locally (eg meetings of local GPs) or at national conferences.

### Early Diagnosis Lung Cancer

The evaluation of the Early Diagnosis Lung Cancer project was presented at the HSJ Social Marketing Conference 2008. Approximately 100 people attended the conference (which included both Public Health and marketing professionals). The project generated a lot of interest and was well received.

### The Better Access Better Services (BABS) - Breast Cancer Care

Breast Cancer Care wanted to find out how to improve access to, and uptake of, its services. The findings are being disseminated both nationally and internationally including a presentation at the European Cancer Conference (ECCO) in Berlin. The charity is writing two papers on the exploratory study conducted with Asian and African Caribbean women, and older women.

Improving access to, and uptake of, our services is a key strategic aim for Breast Cancer Care, as is increasing the diversity of our users, staff and volunteers. It is therefore envisaged the recommendations from the BABS Project will directly impact on the work of the organisation.

**Contact: Karen Scanlon, Head of Research and Evaluation, Breast Cancer Care**
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**www.breastcancercare.org.uk**

# Underpinning activity

## Project management: Key processes/products

**What's your business case/mandate?**
(evidence base, feasibility study).

**Identifying leadership**
(project sponsor, governance, champion, clinical, partnerships).

**Planning**
How long will this take, what are the resources required? What activities need to happen?

**Identifying success criteria**
Where do you want to get to? How will you measure it? Are these processes/data set up already?

**Reporting/ Stage Review**
On going monitoring track the success criteria and viability of the Business Case as you go along. Highlight reporting to Project Sponsor/Board at agreed frequency.

**Lessons learnt log**
(evaluation, monitoring).

**Management of risks, issues and change**

**Stakeholder management**
Who are the stakeholders? Don't forget those who funded project.

**Communications plan**
Who needs to be kept up to date of progress? How often and via what means? How will others learn about this project and its lessons?

# Further information

**World Class Commissioning:**
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_080958

**Transforming Community Services:**
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_093197

**National Cancer Intelligence Network**
http://www.ncin.org.uk

**Cancer Commissioning Guidance and Tool Kit:**
https://www.cancertoolkit.co.uk/

**NHS Evidence:**
http://www.evidence.nhs.uk/AboutUs.aspx

**Making the difference: The Pacesetters beginners guide to service improvement for equality and diversity in the NHS:**
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_086039

**Improvement Leaders' Guide:**
http://www.institute.nhs.uk/index.php?option=com_content&task=view&id=134&Itemid=351

**User Involvement in Commissioning:**
http://www.mccn.nhs.uk/professionals/user-involvement-in-commissioning.php

**User Involvement:**
http://www.user-involvement.org.uk/

**Map of Medicine:**
http://www.mapofmedicine.com/

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NATIONAL CANCER EQUALITY INITIATIVE (NCEI)

# WECAN

## Reducing Inequalities In Commissioning Cancer Services

### Principles and Practical Guidance For Good Equality Working

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