Improving Services: Benefits and pitfalls

Paul Trevatt, Macmillan Nurse Director, North East London Cancer Network
Developing and implementing a community-based prostate health clinic in Newham for hard to reach men

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Acknowledgements

- Cancer Black Care
- Department of Health
- Newham University Hospital NHS Trust (now Barts Health)
- Newham Primary Care Trust
- NCAT (National Cancer Action Team)
- North East London Cancer Network
- Prostate Cancer UK
Purpose of Presentation

• Outline the Newham community-based prostate health clinic in relation to:
  • Case for change
  • Development and implementation of pilot
  • Evaluation and learning
Context

- Prostate cancer is the most common cancer in men in the UK.
- Around 41,000 men are diagnosed with prostate cancer every year. 250,000 men are currently living with the disease.
- Cancer incidence is associated with age with three-quarters of prostate cancer cases diagnosed in men aged over 65 years.
- Prostate cancer is the fifth fastest increasing cancer in males, although much of this may be due to greater use of the PSA test.

Reference CRUK / PCUK
Context

- Prostate cancer is the second most common cause of cancer death in UK men, after lung cancer.
- In 2010 in the UK around 10,700 men died from prostate cancer.
- In the UK, black African and black Caribbean men are 2 or 3 times more likely to develop prostate cancer than white men. Asian men have a lower risk than white men.
- Awareness of prostate cancer appears to be lower in BME communities.

Reference CRUK / PCC
Community-based Prostate Health Clinics

• Due to the complexities involved in diagnosing significant prostate cancers, one suggested model is that men should receive advice and support on prostate health issues at dedicated community-based prostate health clinics. Decision advisors would help men at the following points in the pathway:
  • Men without symptoms considering having a PSA test or equivalent;
  • Men with urinary or other potential symptoms if prostate cancer;
  • Men considering having a biopsy for prostate cancer following a PSA test; and
  • Men diagnosed with benign prostate disease

Decision advisors could be clinical nurse specialists

Cancer Reform Strategy (2007)
Developing the Model

- *The Prostate Cancer Advisory Group (PCAG) helped further shape the pilot*

- **The pilot would:**
  - Be based in a community location
  - Offer open access
  - Have different opening hours to traditional health services
  - Be led by a Clinical Nurse Specialist with support from a local GP and consultant urologist
  - Where possible offer point of care testing
  - Have close links to local support groups and national charities

PCAG (2008)
Case for Change

- Newham has a population of just over 300,000, a jump of almost 25% in the last decade and the second highest percentage increase in the country. It is inner London's most populous borough.
- Life expectancy for men and women is lower than the English national average.
- It has the second worst one-year survival rate for cancer in England. The main factors affecting one-year survival are late presentation by the patient and delayed referral by the GP.
- For men 25% of all deaths are related to cancer.
- Poverty is a major issue. Newham sits within the top three most deprived local authority areas in the country.
- Newham has one of the most ethnically diverse populations, with 61 per cent of the population drawn from Mixed, Asian or Asian British, Black or Black British, Chinese or other ethnic group.

North East London - Newham

Local Support

• The clinical lead of the pilot was also the chair of Cancer Black Care - a national BME cancer charity.
• The chair of Newham Council’s Health and Social Care Scrutiny Commission - Counsellor Winston Vaughan worked hard to raise the profile of the pilot
• Supported by the chair of APA (Association for Prostate Awareness) Ron Reid - local charity based in Newham
• Supported by the chair of the PCT and a number of local GPs with specific interests in the subject
• Supported by the Newham ‘Older and Wiser’ Prostate Cancer United Kingdom (PCUK) project. An African Caribbean volunteer group whose function was to raise prostate cancer awareness within their own community
• Support from North East London Cancer Network which had a strong interest in cancer inequalities (specifically in areas relating to ethnicity)
Ethnicity and Cancer

NELCN hosted a pan London event in partnership with all the other London cancer networks in 2006. Over 100 delegates attended who made healthcare professionals aware of the challenges BME groups faced.

**Findings**

- A) the importance of user engagement
- B) the need to share best practice and not duplicate existing models of working
- C) the need to move away from a Eurocentric style of healthcare delivery (flexible opening, alternate healthcare localities)

**Recommendations**

- Work differently
- Go into communities
- Use local media / radio/ newspapers
- Keep language simple
- Turn research into action
Design and Development (2009-2010)

- In Spring 2009 Newham locality is identified as a pilot site for development and implementation of a community based prostate health clinic.
- A steering group is established. Newham PCT agrees to host the project. Local clinicians are identified to support the pilot.
- NELCN are invited to become involved to ‘lend support and expertise’ in Autumn 2009. Steering group meetings take place locally and at the Department of Health regularly.
- Over the next 12 months (2010) PCUK and King’s College London (KCL) become involved and are invited to join the steering group.
- While service design and clinical pathways are developed the pilot suffers from little to no project management support.
- During the time period the pilot experiences a number of setbacks regarding funding and suitable community venues. Funding is eventually secured through a variety of statutory and voluntary sector sources, but the choice of locality proves to be more challenging.
Service Design

- The objectives of the pilot Prostate Clinic are to:
  - pilot an assessment service in a community setting which is easily accessible and known to the local community
  - provide a service to which men can walk in off the street
  - ensure best compliance through the provision of a ‘one stop shop’ where advice, assessment and results are provided on the same day
  - get men into appropriate treatment as fast as possible where results indicate
  - support development of an effective approach to universal informed choice in relation to provision of information regarding PSA testing
  - explore clients’, providers’ and stakeholders views of the walk in clinic in relation to a variety of factors (prostate cancer awareness, information needs, service satisfaction, etc)

Prostate Steering Group (2010)
Design and Development (2009-2010)

- In the summer 2010 the Newham African Caribbean Resource Centre is identified as a possible site. Initial scoping is positive (location, size, access, facilities) and fits within the aims and objectives of the project plan.

- Outreach visit from local health and safety team challenges the venue as totally unsuitable. Identifies problems relating to age, infection control, safety, and general levels of cleanliness. “A rethink on location is strongly advised.”

- Strongly contested by the clinical lead and other steering group members arguing that the purpose of the pilot was not to recreate a hospital or a polyclinic effect but something innovative that would attract a ‘different demographic than would usually go to the GP’

- The Clinic opening slips on three occasions due to problems with workforce, and equipment procurement.
Operational (2010-2011)

- Soft opening from December 2010 and full opening from Jan 2011 (Monday and Tuesday 14:00 – 19:30). The clinic was formally launched in March 2011 (to tie in with prostate cancer awareness month).

- The clinic offers multi-professional support to men regarding prostate health. Men can visit and ask questions, discuss anxieties and receive information regarding prostate cancer and discuss PSA testing in a supportive environment.

- If men wanted to be examined clinical investigations could be carried out by the CNS / Doctor. PSA testing was not carried out on site but processed at Newham Hospital. Referrals could be made to secondary care. PSA results were communicated to the patient / GP by post.
Communication strategy

• The clinic was advertised through posters, flyers and leaflets, media interviews (radio, newspaper and magazine) and even a bus campaign. Places where men congregated were targeted (religious establishments, community centres, clubs, restaurants and pubs)

• There were two concentrated periods of communication activity (January to April 2011, and November – December 2011)

• 50% of men attended the clinic because of advertising while 25% of men attended as a result of a recommendation by a friend or peer.
Impact of promotion on attendance

- Posters/Flyers (1st Batch)
- Posters/Flyers (2nd Batch)
- Yellow Advertiser feature
- BBC Radio interview
- Newham Recorder feature
- Newham Magazine feature
- Posters & Flyers
- Radio interview and adverts on Voice of Africa Radio
- Bus Campaign
- Newham Hospital newsletter 'Link Up'

Week seen at clinic (date at Mon)

Count

Clinic closed

Evaluation (2012)

• The Clinic operated twice a week (Monday/Friday) opening at 14:00 and closing at 19:30. It ran from December 2010 to December 2011. It operated on 98 days.
• 328 men visited the clinic
• 322 men had a consultation with a health professional
• 59 men were referred to secondary care
• 9 men were diagnosed with prostate cancer
• 3 men were diagnosed with other medical or surgical conditions
• Of those diagnosed with prostate cancer the majority was diagnosed with local disease
Evaluation (2012)

- 55% (n=179) of men visiting the clinic had urinary symptoms. Of those 50% (n=90) had not been to see a GP to discuss their symptoms. The majority did not think their symptoms were serious enough. A small percentage (3%) were referred by their GP.
- Of the 322 men who had consultations with healthcare professionals:
  - 84% (n=271) opted to have a PSA test
  - 74% (n=237) opted to have a DRE
  - 56% (n=181) opted to have their flow rate examined
  - 52% (n=169) opted to have a bladder ultrasound for residual volume
Evaluation (2012)

Demographics

- **35%** of men screened for prostate cancer were born in the UK
- **27%** of men screened for prostate cancer were born in Africa
- **23%** of men screened for prostate cancer were born in the Caribbean
- **46%** of men defined themselves as either black African or black Caribbean and **28%** of men as white
- **75%** of men who attended the clinic were living in areas classified within the 5\(^{th}\) quintile (most deprived)
Evaluation (2012)

Patient Experience

- Both Monday and Tuesday appeared equally popular. More men attended in the afternoon (n=185) but there were a proportion of men of working age who preferred to visit after 5PM (n=71)
- 25% of men attended the clinic through word of mouth
- 83% of men who attended the clinic were extremely satisfied
- 100% of men who attended the clinic would recommend it to others
- Of those using the clinic 22 men lived more than 10KM away
Evaluation (2012)

Economics

• The cost per man per visit was £282 however cost reductions could be achieved in year two and three with workforce re-design and no further procurement costs. Reviewed costs would be £180 per man per visit.

• Costs could be reduced further if the number of men visiting the clinic increased. (The clinic could have supported 12 men visiting per session)

• The savings made by the early diagnosis of prostate cancer / other conditions have not been factored in.
Conclusion (2012)

- Symptomatic men attended the clinic who may not have gone to their GP for advice which suggests that there may be a role for this sort of community based clinic.
- Men were diagnosed with other conditions which suggests that as a model this could be expanded beyond cancer (well man clinic).
- The clinic scored highly in terms of patient experience. Peer to peer referral took place suggesting that men were talking about it locally. Men were prepared to travel to visit the clinic.
- Men appeared to respond to the majority of local advertising (especially the Newham Recorder).
- Large Multi-agency collaborations can work and can lead to a richer more innovative type of project (but they can be challenging to manage).
- As a pilot this may not have been the most cost effective approach to prostate healthcare but larger cost savings could have been made in years two and three.
Learning (2012-2013)

- There was a large period of time between the inception of the pilot and its execution (almost 24 months)
- The lack of project management support resulted in a lack of grip on some occasions
- The project timeline and number of agencies involved meant that inevitably there would be some personnel changes to the pilot (one agency was represented by 5 different individuals over the 24 months). This impacted on the project's development
- Multiple funding streams caused some stress
- Having academic and voluntary sector partners at the beginning of the pilot was a huge benefit and helped shape the pilot’s development
- Monitor and support the communication strategy
- The pilot succeeded on a huge currency of goodwill among pilot staff and steering group members. In the long run this may not be sustainable
- Having a shared project with the voluntary sector was extremely rewarding in terms of learning and operational development
Moving forward

- Prostate clinic referenced in Cancer Reform strategy update 2012
- QIC Awards – November 2012 (Winner and Commended)
- Strong local media response
- Interest expressed from other parts of the country
Thank You for Listening

Any questions or thoughts please contact me on Paul.trevatt@nhs.net
For copies of the King’s College London evaluation please contact jenny.john@kcl.ac.uk