23rd January 2018

Dear members of the Health and Sport Committee,

Thank you for the opportunity to contribute to the Committee’s evidence session on the Detect Cancer Early Programme, as part of the review of the Preventative Agenda in Scotland.

I’m a health services researcher here at the University of Edinburgh, and with Prof David Weller I am currently funded to carry out an evaluation of the Detect Cancer Early programme (as part of a wider PhD study that is examining the role of health system level initiatives in promoting earlier cancer diagnosis). Ms Natalia Calanzani is the researcher on the project, and she and I have worked together in preparing the responses below to the questions provided by the Committee. They focus on DCE, not on other preventative initiatives in Scotland in recent years.

1. To what extent do you believe the Scottish Government’s Detect Cancer Early Programme and the approach by Integration Authorities and NHS Boards is preventative?

- Ms Calanzani carried out initial key stakeholder interviews in 2016. The interviewees indicated that DCE although the focus of DCE was early detection of cancer, it was supportive of interventions incorporating prevention. They also highlighted that more should be done in this area in the long-term, especially with younger people. Stakeholders identified a slow, but perceived, cultural shift towards a focus on prevention, but also acknowledged challenges in changing behaviour, issues regarding autonomy and responsibility regarding one’s health, and barriers due to busy lifestyles and social deprivation.

- Importantly, interviews also highlighted that some of the DCE campaigns would have been incompatible with a focus on prevention. This was the case of the lung campaigns, where emphasising the role of smoking in cancer might have deterred patients from seeking help when noticing symptoms, and could generate distrust as the messages were coming from the government. In this case, the campaigns deliberately avoided talking about prevention.

- DCE received input from the Scottish Cancer Prevention Network. A newsletter was developed as part of this collaboration, targeting patients waiting for their breast screening appointment, but focusing on preventative behaviour and lifestyle changes.

- Although Detect Cancer Early did not focus primarily on prevention, the programme funded discrete work in partnership with Teenage Cancer Trust which may help to
promote preventative behaviours from an early age. Research projects included the investigation of awareness of skin cancer and risk behaviours amongst teenagers (1) and assessing an intervention to increase adolescents' cancer awareness and address help-seeking barriers (2). Some of DCE’s social marketing campaigns also targeted younger people as “influencers”, and may also indirectly influence preventative behaviours in the long term. The “poo song” is an example of such campaign (https://www.youtube.com/watch?v=UrwA_p8H6WY). As with any complex government programme, DCE has also changed over time. The latest Cancer Plan (3) highlights that partnerships with the Teenage Cancer Trust will continue in order to roll out education and awareness programmes in schools.

- Detect Cancer Early had a major emphasis on bowel screening. As bowel screening can remove precancerous polyps, it can be viewed as preventative.
- We do not have specific information about the approach taken by Integration Authorities and individual NHS Boards.

2. Is the approach adequate or is more action needed and is the policy being delivered on the ground?

- Interviews indicate that more work on prevention (as part of DCE) would be helpful, especially with younger people. Hence, continued partnerships with relevant charities and other preventative activities are welcomed. However, it is important to highlight that the programme’s primary aim is to promote early detection of cancer. Prevention is a long-term approach especially with respect to obesity prevention: complementary prevention-specific programmes and strategies are also needed.
- In considering DCE as an early diagnosis strategy, it is a multi-levelled strategy that adopts a health systems approach. Early diagnosis and cancer survival are complex and multifaceted - not a single programme can fully solve such a complex issue. Available evidence on DCE outcomes is described below; the academic evaluation is further investigating DCE processes.
- Perhaps DCE should be seen as one initiative aiming to promote early diagnosis, alongside other much needed public health strategies focusing on prevention, quality of care, treatment and follow-up. Partnerships with research groups are also important to better understand issues such as the role of 1) tumour biology, size and location; and 2) multi-morbidities in cancer survival; and to develop optimum screening and diagnostic pathways for different cancers. Ongoing work on the genetic and molecular profile of cancer, alongside personalised medicine approaches should continue (3). Finally, socioeconomic disparities need to be tackled, adopting a public health approach, not solely focusing on early detection (or prevention).
3. Are the services and Detect Cancer Early Programme being measured and evaluated in terms of cost and benefit?

- The Detect Cancer Early Programme has gathered data for most of its key objectives (see Table 1 below). Reports on cancer staging and bowel and breast screening data are available from ISD Scotland. Rationale and outcomes for the social marketing campaigns were reported by the Leith Agency, Consolidated PR, TNS, Carat, and other organisations involved in these components. Data on consultation due to breast cancer symptoms was collected up to 2013. Discrete data on request for new bowel screening kits and change in uptake was also requested periodically from the Scottish Bowel Screening Programme. Annual Reports from territorial Health Boards submitted to DCE describe how additional funding was used to improve diagnostic capacity. Other policy documents (newsletters, minutes and additional reports) also describe outcome data. These documents focused on assessing benefits, and are being summarised as part of our academic evaluation of the DCE programme.

- We are unaware of any cost-effectiveness analyses associated with DCE. It is not part of our evaluation, although we certainly consider that ideally would have been incorporated in the DCE programme from the start. DCE believed that the programme would be “cost-effective rather than cost saving”.

- There are challenges to show direct benefit of such a complex and multifaceted programme; it is easier to show how the programme may have contributed to the outcomes, and discuss other initiatives/contextual influencers that may also have influenced them (4).

- Initial key stakeholder interviews highlighted challenges when assessing outcomes. Separating the programme from other activities taking place at the same time was described as difficult. DCE was not designed as a randomised controlled study, and conclusions regarding causality would be limited. At times, stakeholders suggested outcomes to be investigated, but then added that data were not available, or were not collected at all. Furthermore, there was the acknowledgement that it takes time for some results (such as changes in survival trends or reduction in lung cancer mortality) to become apparent.

4. Is enough being done to address existing health inequalities in the early detection of cancer?

- The role of deprivation on cancer incidence, mortality and survival was acknowledged by DCE in the implementation plan (5) and incorporated into its strategies. Nonetheless, initial meetings with general practitioners working in Deep End Practices highlighted several concerns about the challenges of reaching, and having an impact on more deprived populations (https://www.gla.ac.uk/media/media_236871_en.pdf).
Deprivation was also taken into account by DCE when weighting the funding for the SQoF initiative in order not to be detrimental to more deprived practices. Social marketing campaigns targeted the most deprived populations, and outcomes for staging and bowel screening uptake indicate that more deprived populations were reached by the programme. Nonetheless, disparities still persist.

Initial interviews with key stakeholders indicate clear knowledge that deprivation could influence cancer incidence, presentation, screening, diagnosis and mortality. Population behaviour towards campaigns was described as variable according to different levels of social deprivation, with the most deprived taking longer to process information from the campaigns, or to act upon them. Stakeholders stated that reducing health disparities was paramount to improve outcomes, but acknowledged that achieving this was beyond the remits of DCE.

A variety of different strategies could be adopted to attempt to reduce inequalities within DCE-related activities, for example testing the use of information materials that are have minimal information and therefore potentially easier to read (and more likely to be read), more campaigns in alternative venue in stadiums and workplaces, providing alternative consultation times, among others. However, as the Committee is well aware, addressing inequalities is a challenging area and even well-developed strategies (such as GP endorsement) do not always work (Raine et al paper).

I look forward to meeting you on Tuesday 6th February.

Yours sincerely,

Dr Christine Campbell

References

### Table 1. Official DCE objectives and outcomes

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<thead>
<tr>
<th>Official objectives in the implementation plan (5)</th>
<th>Available evidence and future plans</th>
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| **1:** To increase the proportion of people with stage 1 disease at diagnosis (as a proxy indicator of survival outcome) and to use performance against a HEAT target as a lever for whole systems approach to improvement – “to increase the proportion of people diagnosed and treated in the first stage of breast, colorectal, and lung cancer by 25% by 2014/2015” | • When checking breast, colorectal or lung cancer combined, 25.5% were diagnosed at Stage 1 for the two-year period 1 January 2015 to 31 December 2016. This corresponds to a 9.2% increase from the baseline (2010 and 2011). In the most deprived areas, 23.8% were diagnosed at stage 1 (a 17.4% increase from baseline). There was also improvement in the proportion of people diagnosed with lung cancer at stage 1 compared to baseline. Hence, the 25% target was not met, but benefits can be seen across time, including across the most deprived populations (6).  
• The academic evaluation of DCE is investigating stakeholder views on this target. Initial interviews indicate that stakeholders were aware that the HEAT target was ambitious and part of a complex programme, and that it would be difficult for it to be met. |
| **2:** To improve informed consent and participation in national cancer screening programmes to help detect cancer earlier and improve survival rates - sQOF target to reward for decrease in non-participation | • There was an 81.1% increase in the number of requests for a replacement bowel kits since the programme started, alongside an increase in bowel screening uptake, including in the most deprived areas in Scotland (from 41.9% to 45.3%) and among men (from 39.6% to 43.6%) (3)  
• The academic evaluation is investigating stakeholder views on the SQOF target. Initial interviews show that stakeholders welcomed the focus on screening (especially bowel screening) as it was a well-established, evidence-based and effective way to identify cancer early. |
| **3:** To raise the public’s awareness of the national cancer screening programmes and also the early signs and symptoms of cancer to encourage them to seek help earlier | • Dozens of reports describe the campaigns, timelines, target groups and approaches; report change in knowledge and awareness over time, across different groups, for different campaigns and tumour types. DCE documents describe changes in campaigns over time due to learning and reduction in available funds. They also summarise campaign components and key outcomes.  
• Breast campaigns generated an increase in consultations due to breast cancer symptoms, but these data ceased to be officially collected in 2013. DCE analyses (described in circulated policy |
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<td>been reduced over time (personal communication)</td>
<td>documents) indicate that increase in consultation was not associated with an increase in cancer diagnoses (7)</td>
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<td></td>
<td>- Our evaluation indicates that stakeholders are supportive of the campaigns. They were described as “bold” and important to inform the population about cancer symptoms and signs. There was the recognition that the campaigns on their own would not be sufficient to completely change population behaviour towards cancer. The symptomatic breast campaign was perceived as useful in terms of lessons learned for future campaigns. The bowel campaign was considered by participants as the one with the most consistent and tangible outcomes.</td>
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4: To work with GPs to promote referral or investigation at the earliest reasonable opportunity for patients who may be showing a suspicion of cancer whilst making the most efficient use of NHS resources and avoiding adverse impact on access

| 4: To work with GPs to promote referral or investigation at the earliest reasonable opportunity for patients who may be showing a suspicion of cancer whilst making the most efficient use of NHS resources and avoiding adverse impact on access | • Internal reports authored by the Roy Castle Lung Foundation are available with outcomes of information sessions with health care professionals; views and experiences were positive |
|                                                                                                           | • An evaluation report about the Primary Care Engagement Programme (in partnership with Cancer Research UK) is available; views and experiences were overall positive (8) |
|                                                                                                           | • There are no documents available that describe changes in terms of efficiency and adverse impact on access |
|                                                                                                           | • The academic evaluation of DCE will describe stakeholder views on the training sessions and the updated referral guidelines. Exploring impact on access, diagnostic delays and efficiency are beyond the scope of the study. |

5: To ensure there is sufficient capacity in the screening programmes to meet the expected increase in those choosing to take part

| 5: To ensure there is sufficient capacity in the screening programmes to meet the expected increase in those choosing to take part | • Minutes from DCE meetings indicate challenges regarding equipment and staff prior to DCE and during initial implementation; in addition to concerns about the impact DCE could have on capacity. |
|                                                                                                           | • DCE documents show more consultations due to breast symptoms and requests for FOBt kits |
|                                                                                                           | • Our initial interviews highlighted capacity challenges for colonoscopy and mammography, with some Health Boards struggling more than others |

6: To ensure that imaging, diagnostic departments and treatment centres are prepared for an increase in the number of patients with early

<p>| 6: To ensure that imaging, diagnostic departments and treatment centres are prepared for an increase in the number of patients with early | • Reports from Health Boards and presentations have data on how extra funding was invested to improve capacity. Local innovations are discussed, but information is limited. Reports also shed light on challenges to improve capacity (e.g. recruitment, |</p>
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<td>disease requiring treatment Note: Additional funding was provided to Health Boards to help cope with increased demand</td>
<td>reduced funding over time) • As before, minutes from meetings indicate challenges regarding equipment and staff, and concerns about DCE’s impact on capacity. Documents also indicate that stakeholders would have liked more precise and consistent estimate about impact on capacity. • The academic evaluation will describe stakeholder views on the additional funding provided.</td>
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7: To strengthen data collection and performance reporting within NHSScotland to ensure progress continues to be made on improving cancer diagnosis, treatment, referral and survival - “Improve data quality by reducing the level of unknown stage at diagnosis and agree the approach for publishing stats”

| 7: To strengthen data collection and performance reporting within NHSScotland to ensure progress continues to be made on improving cancer diagnosis, treatment, referral and survival - “Improve data quality by reducing the level of unknown stage at diagnosis and agree the approach for publishing stats” | • ISD Scotland reports a reduction in the number of “unknown” cases for staging over time (5.3% for the two-year period 1 January 2015 to 31 December 2016) compared to 8.4% during the baseline period. Some of the improvement in staging, or any increase in any staging, is likely due to the reduction of recorded “unknown stages” (6) • The academic evaluation of DCE will describe any stakeholder views on these outcomes |

8: To facilitate further evaluation of the impact of public awareness campaigns on the stage of cancer at presentation and to contribute to research that establishes evidence for the link between late presentation and survival deficit”

| 8: To facilitate further evaluation of the impact of public awareness campaigns on the stage of cancer at presentation and to contribute to research that establishes evidence for the link between late presentation and survival deficit” | • This is a long-term outcome- to our knowledge, it is not being assessed at this stage • The academic evaluation will not investigate this objective further as it is beyond the scope of the study |