Evaluating an ‘incident control’ approach to non-communicable disease

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Abstract

Objectives:

This paper evaluates the application of ‘incident control’ methodology usually applied in communicable disease control to an ‘incident’ of unexplained deaths, specifically to resolve a significant difference in 1-year survival following a lung cancer diagnosis observed between two Clinical Commissioning Groups and the England national average, 2011-14. The purpose of the evaluation was to assess whether a formalised incident control approach is feasible and effective in improving outcomes for non-communicable diseases.

Study Design:

Descriptive; qualitative; process evaluation

Methods:

There were two components to the evaluation: a document review against identified phases of a non-communicable disease incident control framework and a qualitative analysis of semi-structured interviews with stakeholders who had been involved in implementation.

Results:

The findings indicate feasibility of the incident control model, with some limitations. Identified strengths of the model included the articulation of a clear case and incident definition. The structure and stepped phased approach facilitated partner engagement, robust data analysis, action planning and communication strategies. Delays in data publication and the lack of comparable data across different non-communicable diseases present challenges in timely response and prioritisation of ‘incidents’.

Conclusions:

The evaluation indicates value in applying defined incident control methodology to management of non-communicable diseases, especially where there is identification of a potential outlier or a measurable variation i.e. there is a definable ‘incident’ and ‘case’.

Keywords

evaluation; lung cancer; non-communicable diseases; survival; incident control; inequalities

Introduction

The Global Burden of Disease study 2017[1] highlights the increasing prevalence of non-communicable disease (NCD) worldwide and states that progress in reducing mortality from NCDs has stalled or reversed. It also describes the increasing contribution of NCDs to disability and contrasts both these outcomes with the decreasing prevalence and impact of communicable disease (CD).

Knight et al[2] argue that there is much to learn from the health system response to CDs in responding to NCDs. They contrast the mobilisation of resource for outbreaks of communicable disease, supported by systematic surveillance and incident response systems underpinned by legislation with the lack of systematic response to variation in non-communicable disease and argue for parity. They set out an 'incident control' approach to non-communicable disease (NCD), similar to that routinely deployed in the management of CDs[4]: recognising variation from the norm as an 'incident' and following a defined methodology in response which is underpinned by legislation. Incident control methodology in CD includes recognition and definition of an 'incident' e.g. an outbreak; mobilisation of resource across multiple stakeholders; investigation of the data; instigation of control measures and review of activity and outcomes. The 'incident' described by Knight et al[2] is a significant difference in 1-year survival following a lung cancer diagnosis between Clinical Commissioning Groups (CCGs) in Nottinghamshire (population c. 500,000) and the England national average, estimated to be equivalent to 52 additional and potentially avoidable deaths in 2011- 2014[3]. The incident control approach was then used to manage the identified incident with the intention of improving 1-year lung cancer survival in the identified CCG.

This paper provides the formal evaluation of this work, investigating the process and outcomes and making recommendations for future practice. We sought to answer the following questions: a) feasibility and fidelity: was the incident approach feasible and implemented as described, b) what worked well and what was challenging, and c) outcomes: what changed because of this investigation?

Methods

The East Midlands Cancer Alliance initially identified a Clinical Commissioning Group (CCG) with an excess of lung-cancer deaths compared to the national average, and a widening gap over time. An incident was declared and investigated in line with the incident control model proposed by Knight et al[2]. The model is described with the results in Table 1.

The incident control response was supported by a partnership group of 15 professionals drawn from local and regional stakeholder agencies with a role in cancer policy and service planning, including PHE, the National Health Service (NHS) Hospital Trust, the Local Authorities, the Academic Health Science Network (AHSN), Cancer Alliance and the CCG.

The incident was identified in August 2017, activity continued until November 2018 and the evaluation was conducted in June 2019. There were two primary components to the evaluation: a documentation review and a qualitative analysis of semi-structured interviews with stakeholders.

Document review

All documents associated with this incident were provided by the chair of the incident control team and evaluated by a single reviewer (SH). They included minutes and agendas from the incident management team meetings, data analyses and communication material (public-facing and professional). These were reviewed against the phases in the incident control approach recommended by Knight et al[2]. A phase was judged to be fully met if all the proposed guidelines were evidenced. A phase was judged to be partially met if one or more components of the guidelines were not evidenced.

Stakeholder interviews

All 15 stakeholders involved in the incident response were invited for interview by email from the evaluation lead (SH) who also conducted the interviews. See Appendix I for stakeholder profiles. The interview guide (see Appendix II) sought stakeholders' opinions on the process and outcomes, identification of successes and challenges, how this approach differed to business as usual and whether they would work to this model on a future NCD 'incident'. The interview guide was devised in conjunction with MD and piloted with a senior stakeholder. The pilot did not lead to any amendments. Interviews were conducted by phone or face-to-face over the course of 2 weeks. Participants gave consent via email. The interviewer hand-noted responses to the questions in real-time on a pre-printed template and undertook a content analysis to identify key themes within the interviews.

Data was analysed thematically using an inductive approach. SH undertook a preliminary review of the notes, generating initial codes for analysis. The analysis was then re-focussed to combine the codes into 'themes'.

Ethical approval was not required for this study as it was deemed to be health service evaluation.

Results

Document review

The document review included all 18 documents produced during the incident. Of the 6 proposed incident control phases, the documentation showed that 3 were fully met and 3 were partially met, indicating feasibility of the model. Table 1 summarises the activity of the project and how closely it maps to the phased incident control approach described in Knight et al[2] (indicated by full, partial or not met):

Table 1: Process mapped to incident control phases

There was a clear trend of improved 1-year survival during the period 2002 to 2017 across all Nottingham CCGs, however the rate of improvement was slower than the national average. The incident was declared based on data which showed a gap in survival data between two Nottinghamshire CCGs and the national average as described above. Subsequent investigation and analysis as part of the incident management identified a third CCG (Rushcliffe) where there was late diagnosis of lung cancer, also contributing to lower survival rates. Rushcliffe CCG is the least deprived CCG in the Index of Multiple Deprivation[5] and it is therefore unexpected that it would have high rates of late stage diagnosis of lung cancer as late presentation is usually associated with higher levels of deprivation[6]. The most recent data release in 2019[7] does not cover the period of the intervention and therefore it is not possible to demonstrate an impact of this approach on survival.

Stakeholder Interviews

Interviews were conducted with all stakeholders who volunteered (n=7, 47%), six by phone and one face-to-face). There was a high degree of concordance between interviews implying saturation was reached. The key themes arising in the analysis of the interviews were partnership working, data and impact.

Theme 1 - Leadership, partnership working and engagement

The partnership approach was a significant positive aspect to this work. Stakeholders highlighted the commitment and contributions of others, leadership from the Cancer Alliance and PHE and clinical input from the NHS Trust. It was noted that the partnership group was underpinned by effective administrative support and good communication between meetings.

Classification of the survival gap as a ‘major incident’ generated Executive level interest.

‘…on other issues we would write to Execs, for example, performance issues such as waiting times, MRSA etc but not outcomes, it was good to emphasise this…’ ***Commissioner***

The approach mitigated against complexity in commissioning and provider arrangements: prevention led by the Local Authority; diagnosis commissioned by the CCG, treatment commissioned by NHS England and palliative support commissioned by the CCG. Stakeholders reported some lack of clarity regarding overall responsibility, which in turn meant that partners were sometimes unable to mobilise support for the work in their own organisations; this was an issue for external communications, community, primary care and pharmacy engagement. It also felt resource intensive at times, by some partners.

‘…we were up against the fragmented nature of how services are commissioned, planned and paid for…’ ***Commissioner***

Theme 2 – Data: access and analysis

Shared access to data and dedicated analyst support was identified as a key success factor for this project. Stakeholders were able to triangulate data from the ONS, Public Health England and NHS Hospital Trust to understand outcomes at different stages of the cancer treatment journey including stage at diagnosis, waiting times, and survival. Conceptualisation of the survival gap as ‘avoidable deaths’ and the CCGs as ‘outliers’ contributed to a shared understanding of the data and enabled wider engagement with others:

‘[importance of] having confidence that it is more than just a blip in the data…’ ***Commissioner***

‘…I would like to see more routine screening of data to detect outliers earlier, especially where there is not an immediate issue, or we could do something differently, in the same way as field epidemiology [monitors communicable disease] …’ ***Commissioner***

Routine screening of data was raised as a challenge in terms of prioritisation of NCDs to address: currently there is no systematic way of comparing outcomes across disease groups in detail. There may be more avoidable deaths for cardio-vascular disease, or diabetes, or breast cancer; and this may vary within any given geography. Furthermore, other disease groups may present more complexity in terms of partnership involvement and response:

'…There is a challenge e.g. for diabetes where treatment etc is across the system – it wouldn't be so neat, would need a bigger partnership group, more difficult, more factors to consider – complex analysis, how do you know which bit of the system to change? Can we explain this and engage others...?' ***Strategic lead***

Stakeholders reported challenges in comparing data sources over time, due to recent updates in methodology in producing cancer survival estimates[8]. A key challenge was timeliness as there is at least a 2-year time lag in data publication due to patient follow up; registration and analysis:

'…Is this a priority for action <u>now</u> when the stats are old?…' **Public Health Manager**

This time lag was highlighted as a barrier to engagement in 2 instances: senior-level representation on the stakeholder group; and engagement of communications teams.

'… for communicable disease it is reactive, people find a way, time is of the essence. In this case, time doesn't matter so much: 'will do it next week…' need to create a sense of urgency…' ***Communications lead***

Theme 3 – Outcomes and impact

The time lag in data publication (as discussed above) meant that it was not possible to observe an impact on patient one-year survival, however stakeholders attributed the following outcomes to this work:

- Raising awareness of lung cancer and one-year survival as an issue within partner organisations and the public

- Building relationships with stakeholders, specifically by taking a joint quality improvement approach rather than performance management.
- It enabled generation of hypotheses about what the data was showing
- It provided assurance that it was not a healthcare provision issue

Two stakeholders described applying this model to variation in bowel cancel survival and healthy life expectancy. They stated the value in this approach was in ensuring robust data to inform and engage multiple stakeholders in developing actions.

Discussion

We have found that it is feasible to utilise the model described by Knight et al[2] to manage a non-communicable disease incident in a similar approach to communicable disease control. The systematic approach enabled more detailed consideration of the data and targeted action, for example it highlighted an additional CCG with higher than expected late diagnosis rates. We also identified that use of the model to facilitate partnership working was a key factor in the efficiency of the response, alongside dedicated administrative support. It is too early at this stage to determine if the approach will result in a demonstrable improvement in health outcomes.Knight et al[2] contrasted the immediacy of response to CDs in comparison to NCDs and proposed six changes required to achieve parity between management of NCDs and outbreaks of CDs:

- Remove the ‘Strategy paradox’ i.e. successive national plans to tackle NCDs fail to address or respond to locally changing patterns of disease
- Translate surveillance data into meaningful local action
- Develop accountability and ownership of local NCD responses
- Agree a common definition of an NCD ‘incident’
- Implement a standardised incident control approach to investigate NCD outcome variation

- Consider a legislative approach to ensure parity for NCDs

This evaluation showed that application of a prescriptive, stepped incident control approach equivalent to that used in CD incidents is a feasible model to address local inequalities and variation in NCD outcomes. The strength of the data analysis and the wide and effective engagement of partners, including senior leaders were reported as distinct points of difference to usual cancer strategy approaches. The evaluation indicates that there is willingness to approach variation in NCDs with a structured response model, and there is potential for improved outcomes as a result. This chimes with outcomes from other evaluations of collaborative, evidence informed approaches to non-communicable disease response which highlighted the value of multi-disciplinary approaches, data, effective leadership and facilitation[9] and leadership, capacity and readiness to use evidence in decision making[10].

Improving outcomes and reducing inequalities for people with long term conditions and cancer are key themes within the recent England NHS Long Term Plan[11]. However, there are no strategic guidelines for co-ordination of activity across the multiple agencies that have a role in this. This evaluation has highlighted the potential application of a framework for local partnerships to work to.

A key challenge in applying an incident management approach to non-communicable disease is timeliness of the data. CD outbreaks are monitored in ‘real time’, based on a usually rapid onset of illness; robust diagnosis and notification processes and routine screening of surveillance data. Frameworks have been proposed for monitoring and surveillance of NCDs to include risk factors, outcomes, health system response and capacity[12] and the UK has access to this information via ONS, PHE and NHS Trusts. The structured response described in this paper suggests how to integrate this information with local expertise and resources. Even so, NCDs are slow onset, can take time to definitively diagnose or monitor and reporting measures are variable in timeliness and completeness. This means that the response time for the ‘incident’ can be several years (as in this example) and therefore is not responding to current events. The data which informed this response was based on 2015 survival rates[3], and the most recent lung cancer survival data only covers the start of the intervention[7]. There is a risk therefore that any analysis is out of date and therefore incorrect, and any action may be resource wasted. It is also difficult to measure the impact of any intervention as we have discussed.

The strength of this model is in the structure and stepped phased approach. This generates by design: partner engagement, common language, robust data analysis, hypothesis generation, action planning and communication strategies. Challenges are raised by the nature of the difference in characteristics between communicable diseases and non-communicable diseases, for example time to diagnosis, monitoring, long term outcomes. This means that some steps are difficult to adhere to e.g. implementation of control measures, review and knowing when to close the incident. Additionally, the lack of routine data screening for outliers means that there are challenges in prioritising ‘incidents’ and therefore resource.

This evaluation draws from professionals’ reflections on their own and other’s practice in one application of an incident control approach to NCDs. As such it will be subject to recall and reporting bias. The evaluation report on which this article is based was shared with stakeholders for review and comment, no amendments were requested. There were no interviewees from the NHS Provider Trust available to be interviewed, which is a significant limitation of the evaluation as a clinical, provider perspective may differ to that of commissioning or public health leads. The accuracy and quality of the document review is dependent on contemporaneously made notes; adequate recording and filing.

Conclusions

This evaluation demonstrated that there is value in taking a structured and stepped approach to the investigation of poor outcomes of the management of NCDs. Further application of this approach might be beneficial where there is identification of a potential outlier or a measurable variation i.e. there is a definable ‘incident’ and ‘case’. The model facilitates engagement by multiple agencies and introduces clear check points for measuring progress, based on data analysis and stakeholder expertise. More time is needed to measure the impact on health outcomes.

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Author information

Contributions: (1): conceptualisation, methodology, investigation, analysis, data curation, original draft, critical review and editing, project administration. (2): methodology, analysis, critical review and editing. (3): critical review. (4) : conceptualisation, methodology, analysis, critical review and editing, supervision.

Abbreviations

AHSN: Academic Health Sciences Network

CCG: Clinical Commissioning Group

CD: Communicable Disease

EM: East Midlands

NCD: Non- Communicable Disease

NHS: National Health Service

PHE: Public Health England

ONS: Office of National Statistics

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Table 1: Process mapped to incident control phases

Area of response *(met by actions)*	**Proposed NCD guidelines**	**Actions undertaken**
Incident recognition ***Fully met***	*Use routinely collected data for surveillance and early recognition of change in outcomes. Investigate potential incident of sustained or step change with possible single cause or focus of variation*	• Sept 2017, Routine data showed divergence from England 1-year l cancer survival rates in 2 Nottinghamshire CCGs see Figur • Analysis of routes to diagnosis sh high rates of elective and emerge presentation compared to Englan see Figure 2. • Initial investigation did not ascerta clear explanation.
Incident declaration ***Fully met***	*Decision made and recorded at the end of the initial investigation regarding incident declaration and convening of Incident Control Team (ICT) from appropriate partner organisations*	• Sept 2017, Decision made and recorded
Incident Control Team ***Partially met***	*ICT held as soon as possible and within ten working days of decision to convene all agencies/disciplines involved in investigation and control represented at ICT meeting* *Roles and responsibilities of ICT members agreed and recorded* *Lead organisation with accountability for incident management agreed and recorded*	• 1st meeting held November 2017. PHE to be lead organisation • No formal documentation of roles responsibilities, but actions are allocated to group members.
Incident investigation and control ***Partially met***	*Urgent control measures indicated from initial investigation agreed and implemented* *Outcome deterioration definition agreed and additional data to support investigation sourced from ICT members/partner organisations.* *Descriptive epidemiology of routine and additional data undertaken and reviewed at ICT to aid hypothesis generation. To include: outcome trend over time; description of key*	• No urgent control measure indicat initial investigation as underlying reasons for variation not clear • No deterioration definition agreed. • Additional data sought from trusts statistical neighbours. • Epidemiology described which highlighted geographical variation diagnosis, including unexpected l stage diagnosis in more affluent a • Hypotheses: late stage diagnosis, of awareness by the public. • No underlying variation in health c provision was identified.

Supplementary Material

Appendix I

Table I.i Interview guide

Name, Job role, Role/contribution to group:
Can you describe the overall project to me?
What worked well?
What was challenging?
Did this approach feel different to ‘business as usual’ approaches? In what way?
What changed because of this project? What was the impact/outcomes?
Would this approach be applicable to other non-communicable disease ‘incidents’
What have you learned/ Would you do anything differently next time?
Can I contact you again for any clarification?

Appendix II

Summary of Stakeholders

Academic Health Science Network: develop collaboration across all sectors involved in healthcare - the NHS, social care and public health, universities, third sector and industry - to identify, test and spread ways to drive NHS transformation. The AHSN is part of the Cancer Alliance.

Cancer Alliance: bring together local senior clinical and managerial leaders representing the whole cancer patient pathway across a specific geography.

Clinical Commissioning Group: commission most of the hospital and community NHS services in their geography

Local Authority Public Health: lead and commission population level interventions to improve and protect health, prevent disease and reduce health inequalities in their geography

NHS Hospital Trust: provide NHS services, treatment

Public Health England: works at national and regional level to improve health and reduce inequalities

T**able II.i** Interviewee profile

Organisation	Number of respondents
AHSN	1
CCG	1
Local Authority	1
PHE	4

Job roles	Number of respondents
Analyst	2
Commissioner	2
Communications	1
Public health manager	1
Strategic leadership	1