

What are the challenges of collecting and analysing data in primary care?

Lessons learned from a feasibility study in ~~six~~^{five} general practices in Lothian, Scotland

Dealing with Data Conference
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National Awareness and Early
Diagnosis Initiative (NAEDI)

Outline

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1. Background

- Bowel cancer 3rd most common cancer in Scotland¹
 - Symptoms may not be apparent until cancer is advanced²
- Bowel screening helps to identify cancer before symptomatic presentation
 - If found in earlier stages, treatment is more likely to be effective²
 - In Scotland, those aged 50-74 are invited every 2 years
 - Participation is low (56.1%)³ and worse in more deprived areas
 - Primary care has a crucial role in increasing participation



Bowel Screening:
Scottish Bowel Screening Programme



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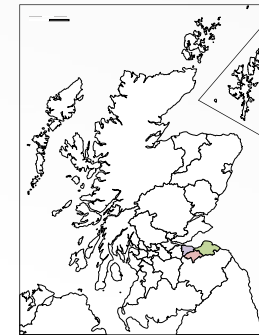
1. ISD Scotland. Cancer in Scotland. October 2014. Available from: http://www.isdscotland.org/Health-Topics/Cancer/Publications/2014-10-28/Cancer_in_Scotland_summary_m.pdf
2. Damery S, Smith S, Clements A, et al. Evaluating the effectiveness of GP endorsement on increasing participation in the NHS Bowel Cancer Screening Programme in England: study protocol for a randomized controlled trial. *Trials*. 2012;13(1):18
3. Scottish Bowel Screening Programme. Key Performance Indicators Report: May 2014 data submission.

2. Brief project description

- Project has three parts
 - Strand 1: database analysis
 - Strand 2: development and refinement of intervention
 - Strand 3: testing the intervention in five practices in Lothian

Study aim: we are testing whether an evidence-based intervention in primary care is a feasible way to engage with non-responders to screening

- Study duration: 4 months in each practice (Jan – Sep 2015 across all practices)
- Each intervention 1-5 min
- Mechanisms to identify non-responders
- Approach patients during a consultation



2. Brief project description (cont.)

- Intervention informed by evidence on reasons for non-participation and psychological theories

Post-intervention questionnaires and interviews

Flowchart and guidance sheet for staff

Intervention proforma

Patient leaflet and freepost envelope

3-4 questions



3.1 Identified challenges and adopted strategies: setting up the scene

1. Governance and staff changes

Challenges

- Changes re. ethical/governance reviews
- Staff changes

Strategies

- Audit trails and change of order of strands
- Minutes, frequent meetings and handover

2. Setting up non-responder status

Challenges

- ≠ resources, computer systems and codes

Strategies

- Allocate time for data entry
- Liaise with the Bowel Screening Centre
- Learn about ≠ computer systems and codes

3. Dealing with practice constraints

Challenges

- 1st visit (duration, attendance, setting)
- Lack of access to GPs and gatekeeping

Strategies

- Adapt presentations; prepare handouts
- Insist, but be aware that access may not always be possible



3.2 Identified challenges and adopted strategies: ensuring consistency

1. The “black box”

Challenges

- No control of what happens after leaving the practice

Strategies

- Training session provided to practice team
- Monthly visits, concurrent data entry and creation of a diary
- Use of informative data labels in SPSS

2. Start and end dates by practice

Challenges

- Practices at \neq stages of data collection

Strategies

- Create/update progress tables and tasks
- Frequent contact with practices

3. Digital vs. paper proforma

Challenges

- Data in different formats
- Comments not verbatim
- Additional steps to access data

Strategies

- Compare computer reports with raw data
- Have required approvals in place



Original proforma

Practice name:			
Primary care role (i.e. GP, practice nurse):		Staff name:	
Date:	Patient sex:	Patient age:	Duration of intervention (min):
Reasons for consultation:			
Intervention accepted? <input type="checkbox"/> Yes <input type="checkbox"/> No	Leaflet given? <input type="checkbox"/> Yes <input type="checkbox"/> No	Leaflet completed in practice? <input type="checkbox"/> Yes <input type="checkbox"/> No	
Comments (patient's reaction, challenges faced, points observed)			

Digital proforma

SB Bowel screening BI.

Bowel Screening Brief Intervention

Brief intervention done Brief intervention 04/03/2015
Bowel cancer screening programme leaflet given

Optional

Duration of brief intervention for non-responders to bowel screening invite minutes
Add comments

BI declined Refuse procedure NOS 04/03/

OK Cancel



3.3 Identified challenges and adopted strategies: understanding the context

1. Current initiatives and practice deadlines

Challenges

- DCE, DES and QOF: impact on workload

Strategies

- Be aware of the context and accept delays

2. Severe time constraints

Challenges

- Practices have \neq priorities and are restricted in terms of time and resources
- Group interviews, poor RRs
- Pressure on GPs, late withdrawals

Strategies

- Keep in touch without overwhelming team
- Accept limitations of data collection and record possible reasons
- Be prepared for surprises, log everything

3. Availability of materials

Challenges

- Practices ask for more materials than they actually need – they work as a reminder

Strategies

- Keep track of number of distributed materials
- Have more materials than you actually need

3.4 Identified challenges and adopted strategies: making sense of the data

1. Data limitations

Challenges

- Not possible to know the denominator
- Not possible to have individual data

Strategies

- Acknowledge limitations of using real data and describe implications in reporting

2. Strategies already in place

Challenges

- Some practices already had systems in place to engage with non-responders

Strategies

- Ask questions, take photographs, create and update intervention logs for each practice

3. Proforma completion

Challenges

- Missing data in digital proformas
- Patient names added by accident
- Missing practice names and job titles

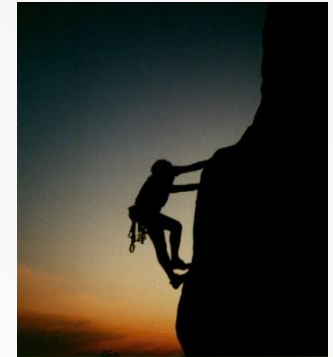
Strategies

- Acknowledge limitations of procedure
- Check proformas one by one in the practice
- Have staff name lists, check websites
- Write unique, informative IDs in the back of proformas to trace back data



4. Take home messages

- Potential versus reality
 - Things do not always go as planned
 - Be aware of gatekeeping, time and resource constraints in primary care
- Be organised
 - Create logs, audit trails, and data entry diaries to understand your decisions along the way and to help you interpret your data
 - Create unique IDs to be able to trace back your data
 - Keep control of amount of materials distributed and still available



Thank you for listening!

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