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

Lessons learned from a feasibility study in six general practices in Lothian, Scotland

Dealing with Data Conference
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Outline

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2. Brief project description
3. Identified challenges and adopted strategies
   1. Setting up the scene
   2. Ensuring consistency during data collection
   3. Understanding the health care context
   4. Making sense of the collected data
4. Take home messages

The Beginning
1. Background

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

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

- Intervention proforma
- Patient leaflet and freepost envelope
- 3-4 questions
- Post-intervention questionnaires and interviews
- Flowchart and guidance sheet for staff
## 3.1 Identified challenges and adopted strategies: setting up the scene

### 1. Governance and staff changes

<table>
<thead>
<tr>
<th>Challenges</th>
<th>Strategies</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Changes re. ethical/governance reviews</td>
<td>• Audit trails and change of order of strands</td>
</tr>
<tr>
<td>• Staff changes</td>
<td>• Minutes, frequent meetings and handover</td>
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</tbody>
</table>

### 2. Setting up non-responder status

<table>
<thead>
<tr>
<th>Challenges</th>
<th>Strategies</th>
</tr>
</thead>
<tbody>
<tr>
<td>• ≠ resources, computer systems and codes</td>
<td>• Allocate time for data entry</td>
</tr>
<tr>
<td></td>
<td>• Liaise with the Bowel Screening Centre</td>
</tr>
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<td></td>
<td>• Learn about ≠ computer systems and codes</td>
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### 3. Dealing with practice constraints

<table>
<thead>
<tr>
<th>Challenges</th>
<th>Strategies</th>
</tr>
</thead>
<tbody>
<tr>
<td>• 1st visit (duration, attendance, setting)</td>
<td>• Adapt presentations; prepare handouts</td>
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<tr>
<td>• Lack of access to GPs and gatekeeping</td>
<td>• Insist, but be aware that access may not always be possible</td>
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### 3.2 Identified challenges and adopted strategies: ensuring consistency

#### 1. The “black box”

<table>
<thead>
<tr>
<th>Challenges</th>
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</tr>
</thead>
<tbody>
<tr>
<td>- No control of what happens after leaving the practice</td>
<td>- Training session provided to practice team</td>
</tr>
<tr>
<td>- Practices at ≠ stages of data collection</td>
<td>- Monthly visits, concurrent data entry and creation of a diary</td>
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<tr>
<td></td>
<td>- Use of informative data labels in SPSS</td>
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#### 2. Start and end dates by practice

<table>
<thead>
<tr>
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</tr>
</thead>
<tbody>
<tr>
<td>- Practices at ≠ stages of data collection</td>
<td>- Create/update progress tables and tasks</td>
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<td></td>
<td>- Frequent contact with practices</td>
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</table>

#### 3. Digital vs. paper proforma

<table>
<thead>
<tr>
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</tr>
</thead>
<tbody>
<tr>
<td>- Data in different formats</td>
<td>- Compare computer reports with raw data</td>
</tr>
<tr>
<td>- Comments not verbatim</td>
<td>- Have required approvals in place</td>
</tr>
<tr>
<td>- Additional steps to access data</td>
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</tbody>
</table>
### 3.3 Identified challenges and adopted strategies: understanding the context

#### 1. Current initiatives and practice deadlines

<table>
<thead>
<tr>
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<th>Strategies</th>
</tr>
</thead>
<tbody>
<tr>
<td>• DCE, DES and QOF: impact on workload</td>
<td>• Be aware of the context and accept delays</td>
</tr>
</tbody>
</table>

#### 2. Severe time constraints

<table>
<thead>
<tr>
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</tr>
</thead>
<tbody>
<tr>
<td>• Practices have ≠ priorities and are restricted in terms of time and resources</td>
<td>• Keep in touch without overwhelming team</td>
</tr>
<tr>
<td>• Group interviews, poor RRs</td>
<td>• Accept limitations of data collection and record possible reasons</td>
</tr>
<tr>
<td>• Pressure on GPs, late withdrawals</td>
<td>• Be prepared for surprises, log everything</td>
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</table>

#### 3. Availability of materials

<table>
<thead>
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</thead>
<tbody>
<tr>
<td>• Practices ask for more materials than they actually need – they work as a reminder</td>
<td>• Keep track of number of distributed materials</td>
</tr>
<tr>
<td></td>
<td>• Have more materials than you actually need</td>
</tr>
</tbody>
</table>

**DCE:** Detect Cancer Early  
**DES:** Directed Enhanced Services  
**QOF:** Quality and Outcomes Framework
### 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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