

# Patients as partners in developing self management solutions:

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Guide to capturing patient and  
carer insights to inform  
commissioning

## Guide to capturing patient and carer insights

### Introduction

A key element of the Patients in Control Programmes in the South and Midlands/East of England regions was to really understand what was important to patients and carers in managing their own care more successfully.

We wanted to get as many views as possible, to get a real sense of what's important to patients and carers.

### Defining the challenge and needs

The programme presented a number of challenges that needed to be addressed through careful and considered design and implementation.

- **The nature of the overall programme objectives and purpose**

The need to develop a methodology for engagement that could be rolled out plus the need to gather insight and develop a range of materials to aid service development and support. This meant the programme needed to evolve and offer a degree of flexibility in terms of methodology and project management.

- **Breadth of coverage versus depth of understanding**

The aim was to include as many patients and carers as possible in order to deliver a strong and compelling set of findings to influence future commissioning and service delivery.

- **The need for inclusivity**

Whilst the key themes to be addressed and developed through the programme were generic, it was important to include as wide a range of different types of people as possible. The following elements needed to be taken into consideration:

- *Demographics* – to cover a wide spread of ages and socio-economic backgrounds
- *Different conditions and circumstances* – for example, physical and mental health conditions, people with different levels of mobility and self-sufficiency, working and non-working people
- *Ethnic background* – engagement with people from a wide range of ethnic, cultural and religious backgrounds
- *Carers and patients* – the sample for all forms of engagement should include both, together or separately as appropriate.

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### • **Supporting engagement activity**

Voluntary organisations/charities are a key source for finding and supporting patients and carers to get involved in the programme. Both those delivering services 'on the ground' and those managing organisations should ideally be included to ensure a wide network of patients and carers are found and involved, and to ensure a full range of perspectives are included in the feedback.

Clinical Commissioning Groups (CCGs) and Area Teams (ATs) were key stakeholders in contributing to finding patients and carers to take part in the programme and then in embedding the findings in their local commissioning activities. Early involvement of the CCG helped to drive the 'buy-in' to the process and add credibility to the findings.

### **Selecting the best methodology**

The following factors had to be taken into account when deciding the best approach to get as many insights as possible:

- What were the specific objectives of capturing the insights?
- How would the insights and outputs be used? By whom?
- Who was the target audience feedback was wanted from?
- How would they be reached?
- What existing or established communication channels and patient networks could be used?
- What time was available? When did this work need to be completed by?
- What budget was available?
- What blocks might there be and how might these be addressed/overcome?

### **Selected methods**

- On-line survey –sent out to all CCGs/ATs and voluntary organisations (via umbrella group(s)) in order to: promote the programme; assess 'buy in'; identify potential groups across the South.
- Group discussions
- Depth interviews (telephone)
- Individual case studies
- Group discussions
- Co-design group discussions

## Guide to capturing patient and carer insights to inform commissioning

### Online survey

<b>Description:</b>	<ul style="list-style-type: none"> <li>• Self-completion questionnaire. Individual organisation-specific link (to track responses). Conducted as an initial stage (with the findings built on/used during the co-design activity in more detail)</li> <li>• Mixture of closed, pre-coded, and open-ended questions to reduce time/cost of analysis but also allow for some detailed insights to be shared</li> </ul>
<b>Benefits:</b>	<ul style="list-style-type: none"> <li>• Reaches a large number of patients and carers, providing a degree of credibility and weight to the programme overall</li> <li>• Adds surety and confidence to the conclusions and actions taken</li> <li>• Relatively simple and cost-effective to set-up and administer</li> </ul>
<b>Draw-backs/challenges:</b>	<ul style="list-style-type: none"> <li>• Response rates to self-completion surveys can be very low</li> <li>• Does not provide deep and detailed exploration of needs and attitudes</li> </ul>
<b>Process:</b>	<ul style="list-style-type: none"> <li>• Explanation of programme, purpose of survey and invitation to disseminate among patients and carers networks sent to each CCG and AT across the two regions</li> <li>• Results monitored through external market researchers and programme team, to send further invites and prompts</li> <li>• Overarching report completed by region</li> <li>• Individual reports for each organisations with more than 20 responses</li> </ul>

### Follow-up telephone interviews

<b>Description:</b>	<ul style="list-style-type: none"> <li>• Follow up telephone interviews with some respondents from the above, to gain more in-depth insights on some of the key responses</li> </ul>
<b>Benefits:</b>	<ul style="list-style-type: none"> <li>• Low cost (reduces travel time)</li> <li>• Flexible (able to engage with participant at relatively short notice and at any time of the day)</li> <li>• Provides a degree of anonymity and security for some</li> <li>• Lower level of commitment for participants can increase cooperation/reduce drop-out</li> </ul>
<b>Draw-backs/challenges:</b>	<ul style="list-style-type: none"> <li>• Lack of interaction limits creativity and debate</li> <li>• Lack of face-to-face contact diminishes the rapport between interviewer and participant</li> <li>• Use of visual stimulus material is difficult</li> <li>• Limited in terms of breadth of coverage</li> </ul>
<b>Process:</b>	<ul style="list-style-type: none"> <li>• Approx. 15-30 minutes in duration</li> <li>• Conducted over the telephone at a time suitable to participant</li> <li>• Exploration of earlier key responses</li> </ul>

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### Individual in-depth interviews

<b>Description:</b>	<ul style="list-style-type: none"> <li>• One-to-one interviews exploring individual perceptions in detail</li> <li>• Whole day or two half days</li> </ul>
<b>Benefits:</b>	<ul style="list-style-type: none"> <li>• Enables full and detailed exploration of individual's experiences, perceptions and preferences</li> <li>• Provides intimate and private environment for candid discussion (can be conducted in participants' homes if necessary)</li> <li>• Easy to organise – dependent only on interviewee and interviewer</li> </ul>
<b>Draw-backs/challenges:</b>	<ul style="list-style-type: none"> <li>• Person being interviewed may feel this approach is too intrusive</li> <li>• May cover same ground many times</li> </ul>
<b>Process:</b>	<ul style="list-style-type: none"> <li>• Date, timings, venue agreed between both parties</li> <li>• Time allowed to reflect, be silent</li> <li>• All conversation captured – ideally with recording equipment</li> <li>• Write up shared and checked with interviewee</li> </ul>

### Facilitated patient/carers groups

<b>Description:</b>	<ul style="list-style-type: none"> <li>• Interactive, facilitated discussion involving patients and/or carers reflecting their perceived priorities in relation to managing their own care (then linked to above insights work)</li> <li>• Recruited through above or CCG-specific patient/carers networks or local voluntary organisations' networks</li> </ul>
<b>Benefits:</b>	<ul style="list-style-type: none"> <li>• A creative environment which encourages debate and interaction</li> <li>• Good method of engaging people with an interest in the topic under discussion</li> <li>• Can explore issues as they arise, individually and collectively</li> </ul>
<b>Draw-backs/challenges:</b>	<ul style="list-style-type: none"> <li>• Can be difficult for some people to get to groups (either due to geography or finding the time)</li> <li>• Some people may find it difficult to share their experiences with others</li> <li>• Can be difficult to encourage participation among some groups (e.g. younger people)</li> </ul>
<b>Process:</b>	<ul style="list-style-type: none"> <li>• Approximately 3 sessions, 2.5 hours in duration, with fixed membership and facilitation</li> <li>• Approx. 8-12 participants per group</li> <li>• Held in easily accessible venues</li> <li>• All sessions recorded and final report made available to sponsoring organisation</li> </ul>

### Facilitated Co-design Group

See separate guide

### For further information

Go to <http://www.southeastcsu.nhs.uk/participation>

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