Involving patients in service improvement activities

Summary paper

**Accelerate, Coordinate, Evaluate (ACE) Programme**

An early diagnosis of cancer initiative supported by:
NHS England, Cancer Research UK and Macmillan Cancer Support

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Patient champion for the ACE Programme:
Dr Rosie Loftus, Chief Medical Officer at Macmillan Cancer Support

About the ACE Programme

The Accelerate, Coordinate, Evaluate (ACE) Programme is an early diagnosis of cancer initiative focused on testing innovations that either identify individuals at high risk of cancer earlier or streamline diagnostic pathways. It was set-up to accelerate the pace of change in this area by adding to the knowledge base and is delivered with support from: NHS England, Cancer Research UK and Macmillan Cancer Support; with support on evaluation provided by the Department of Health’s Policy Research Units (PRUs).

The first phase of the programme consisted of 60 projects split into various topic-based clusters to facilitate evidence generation and learning. The second phase (pilots live from January 2017) comprises five projects exploring Multidisciplinary Diagnostic Centre (MDC) - based pathways. The learning from ACE is intended to provide ideas and evidence to those seeking to improve local cancer services. The evaluations and findings are produced independently, and are therefore, not necessarily endorsed by the three supporting organisations.
Introduction

Improving overall patient experience of cancer diagnostic pathways was one of the aims of the ACE Programme. Involving people affected by cancer in service (re-)design initiatives is recognised as an important means of achieving this.

This summary paper outlines the ways in which ACE projects sought to involve patients in the design and delivery of their early diagnosis projects. It shares on-the-ground learning in terms of the challenges they faced and the methods of engagement found to be successful.

Analysis and approach

A patient involvement survey was sent to 47 ACE projects (July 2015). Projects were excluded from the survey where it was known that patient involvement was not applicable e.g. audits. A total of 37 responses were received, including from projects that indicated no patient involvement. Data from all 37 responses has been analysed, with some answering supplementary questions (April 2016). Survey in appendix 1. The survey provides a snapshot in time and captures both what projects had done and planned to do. It is likely that patient involvement plans will have evolved as projects progressed, which is not captured here.

When and why to involve patients

Involving patients throughout the project lifecycle

The stages of project development from a patient involvement point-of-view were defined as: preparation, design, launch/implementation, ongoing, and feedback/evaluation. Examples of engagement from ACE projects can be found at each of these stages. Those projects that involved patients at the outset were more likely to indicate an intention to involve patients on an ongoing basis throughout the project lifecycle.

Using patient insight to inform the design of the initiative

Projects whose primary objective was to influence the behaviour of patients all sought to involve patients in the preparation and design stages. For example, those ACE projects involved in improving bowel screening uptake and screening uptake amongst vulnerable groups, and those seeking to identify individuals at high risk of lung cancer. Consideration, based on project objectives, was given as to whether to target a broad cross-section of patients or to target specific groups such as different ethnic groups, those with learning disabilities and those from distinct local communities.

Consulting with patients prior to the design of the intervention or pathway generated insights based on actual patient experience and also on patient attitudes. For example, projects explored barriers to cervical screening amongst South Asian women and attitudes to lung cancer in advance of designing the ‘lung health check’ for people at high risk of lung cancer.

“The project was initiated following a local piece of insight work undertaken by Kirklees Healthwatch, which investigated the barriers to cervical screening in South Asian women. This work involved a range of methods of engaging with the local South Asian community. E.g. focus groups and interviews”
Nine reasons to involve patients

Based on the survey, patient involvement can provide the following benefits:

- Ensures that the design and focus of campaign materials will have the desired impact on the target audience.
- Ensures that engagement activities are selected based on feedback on what connects best with the target audience.
- Ensures information materials are fit-for-purpose for each target patient group.
- Ensures changes to services are designed based on the knowledge of what works or doesn’t from the patients’ perspective, which might otherwise be missed.
- Provides feedback on new services that can suggest adjustments which will help improve patient experience and satisfaction, which will also be an important element of the service business case.
- The act of involving patients in the design of an initiative helps secure local ownership of the problem, buy-in to the solution and traction with the target community through word-of-mouth, amongst family, friends, neighbours and colleagues.
- Generates renewed commitment from the project team as they make an emotional connection between their work and patient benefit.
- Helps to increase numbers of patients consenting for their data to be included in research studies.
- Provides additional meaningful input into health equity audits and health impact assessments required on the introduction of new policies and services.

“We believe care should be wrapped around patients’ needs, not organisational structures. For that reason, patient involvement is very important to us”

“The users of services have a pivotal role to play in service redesign and developments which affect patients. [We] believe the voices and opinions of patients and carers is as important as that of the clinicians, service providers and commissioning teams. The ACE Programme has allowed the lung cancer team to really endeavour to make transformational changes to services. This would however not be possible if the voice and opinions of patients were not considered”
Challenges to think about upfront

Involving patients in projects was not always straightforward. Based on the reported experiences of ACE projects, a list of challenges is presented below, which if addressed up-front should result in a more effective patient involvement strategy.

Project-related challenges

- Not enough time allowed for patient engagement activities within the overall project timeline.
- Insufficient capacity within the project team / patient engagement lead.
- Not being aware of organisational changes in partner agencies who are acting as or providing patient representatives that subsequently put at risk the promised support.
- Not considering ethical issues up-front can result in delays or in not being able to proceed with the original engagement plan.

Patient-related challenges

- Managing expectations of patient representatives in terms of: level of influence; time commitment, particularly where the commitment is ongoing; and, how quickly change on the ground will happen.
- Obtaining robust and sufficient patient input, on a regular and consistent basis.
- Ensuring that patient involvement is meaningful and beneficial to patients.
- Cancer patients may just not want to get involved at any level in an improvement project as they have other more pressing priorities.

Engagement-related challenges

- Relationship building and awareness raising takes time, and whilst it might be tempting to shortcut this, it is important to find different ways to engage with patients.
- Difficulties with recruiting sufficiently diverse patient groups.
- Low local interest in people wanting to get involved in patient feedback activities.

Potential methods of involvement

Listed below are the main methods used by ACE projects to secure patient involvement.

Recruitment methods

- Using established patient reference or community groups as a source of patient representatives, e.g., Healthwatch, National Voices, Patient First, Black Health Agency, MENCAP, local cancer friendship groups, local voluntary groups that promote early cancer signs and symptoms, etc.
- CCGs have often put in place specific patient representative groups to support local service improvement initiatives.
- Adverts in the local press.

“When the project had ups and downs and the patient representatives got frustrated, it was rather hard to keep them engaged”
Involvement methods

- Patient representatives attending project meetings, including Clinical Reference Group (CRG) meetings, project boards and steering groups.
- Quantitative and qualitative surveys, e.g., patient experience survey; awareness surveys (outdoor, online, a range of patient group meetings).
- Data from patients completing a Cancer Health Needs Assessment.
- Qualitative research methods, e.g., focus groups; attending other organisations local group sessions; depth interviews, using a semi-structured format or an unstructured one-to-one conversation between patient and the clinical lead.
- Using Healthwatch, or similar local organisation, to provide comments and feedback specifically to a brief or acting on insight work already carried out.

To note there are other research methods available beyond those noted here.

Useful tips for engaging patients

Consider:

- Holding engagement sessions at various times to cater to different schedules.
- Translation needs of different patient groups (written, oral) and use formats suitable for the audience, e.g., for those hard of hearing or with literacy problems.
- Transport needs of patients in attending engagement sessions.
- Whether feedback should be provided anonymously.
- How best to ensure the patient group mirrors the service target patient group.
- If you have allocated sufficient budget to support the different customisation aspects of patient involvement.
- Evaluating your patient engagement activities.

A broader set of good practice guidelines and tips for patient involvement can be found in appendix 2 (from Cancer Research UK, Macmillan Cancer Support and Healthwatch).

Conclusion

Engaging with those affected by cancer is an important means of improving the effectiveness of service improvement interventions. Projects maximise the benefit conferred from patient involvement when they involve patients throughout the project lifecycle. The trend towards increasingly proactive and targeted interventions, particularly relevant to the drive to reduce health inequalities, emphasises the continued importance of patient involvement.

Contact ACE

If you have any queries about ACE, please contact the team at: ACEteam@cancer.org.uk.

In addition, you can visit our webpage: www.cruk.org/ace where we will publish news and reports.
### Appendix 1

**ACE Programme: Patient Involvement Questionnaire – Sent July 2015**

**Can you tell us how you have involved patients in your ACE project, eg:**

- What kind of patient engagement / involvement activities have been undertaken?
- Are there patient representatives on the project board?
- Has there been consultation with patient groups, public information meetings patients can attend, focus groups, regular liaison with patient representatives, working with local HealthWatch etc?

**Can you tell us at what stages of your project have patients been involved, e.g. in initial project design, ongoing etc**

**Can you tell us what steps have you taken to ensure input from a broad range of patients including BME groups, people with disabilities and other seldom heard groups?**

**Can you tell us if you have asked patients involved in your project about their experience of working with the project? If so, how was this done or how will this be done?**

**Any other comments?**
### Additional Questions – sent April 2016

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<th>Question</th>
<th>Answer</th>
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<td><strong>What were the benefits to ACE programme in your patch by having patient involvement?</strong></td>
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<td><strong>Why is patient involvement important?</strong></td>
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<td><strong>Do you normally engage with patients like this or did you do it differently for the ACE programme?</strong></td>
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<td><strong>Did the patient’s perspective manage to influence secondary care perspective and to what extent?</strong></td>
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<td><strong>At which stage was patient involvement most useful and easiest?</strong></td>
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<td><strong>Do you have a patient engagement lead, or similar, within your organisation? If so, have you utilised them for the ACE project?</strong></td>
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### Benefits

### Challenges

### Patient quotes
ACE Programme: No Patient Involvement Survey – sent April 2016

<table>
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<th>What were the barriers to involving patients in your project?</th>
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<td>• Was it inappropriate, unfeasible or not relevant to your project? If so, please explain.</td>
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<tr>
<td>• Were you unable to involve patients for any reason? If so, please explain?</td>
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| Do you think that your project would have benefitted from patient input? Please explain. |

| Would you normally involve (or try to involve) patients in your projects? If so, why do you think it wasn’t possible for this ACE project? |

| Any other comments? |
Appendix 2: Good practice guidelines for patient involvement

Cancer Research UK: a quick guide to involving people affected by cancer in service design

**IN INVOLVING PEOPLE AFFECTED BY CANCER IN SERVICE DESIGN**

A quick guide to involving people affected by cancer

“Who better to involve in the development of a cancer service than those who have direct experience?” – Cancer patient

“I’d like the process to offer a genuine chance to make a difference in delivering real improvements” – Cancer patient

- Be clear on what you hope to achieve by involving people affected by cancer.
- Explain where there is and isn’t scope to influence.
- Identify who you need to involve, e.g. people with current or recent experiences of cancer.
- Consider which involvement methods will work best for the people you need to involve.
- Factor in appropriate time and resource.

“A personal approach is important, people may need to have their confidence built to recognise that they’re an expert in how they feel and what they want” – Cancer patient

- Explain how people can get involved using language they will understand.
- Use a variety of ways to reach out to different people and consider the timing of asking for their input e.g. posters that signpost to more info, face to face conversations, written correspondence, social media, follow up from other feedback people have given.
- Be clear on what you expect from people involved, and what they can expect from you.

“A lot of us want to give something back, but we can’t repay those who went before us. So we try to improve things for the future” – Cancer patient

- Involve people from an early stage.
- Make people comfortable, ask what support might help them to contribute.
- Value people affected by cancer as experts.
- Listen to, respect and learn from their experiences.
- Include people affected by cancer in the review and development of services.

“If you’re doing something different because that is what patients wanted, then say so” – Cancer patient

- Thank people for their contribution and for giving up their time.
- Explain how you’ll use the feedback and how you’ll monitor the difference made.
- Update people and be honest about the impact of the involvement.
- Continue to involve people to ensure services best meet their needs.

For more information, get in touch involvement@cancer.org.uk

Involving patients in service improvement activities v1
Macmillan Cancer Support: ten guidelines for designing participation and twelve top tips

**Ten guidelines for designing participation**

These guidelines have been developed to ensure that community led events are designed around the needs of the participants and to maximise the ability of different groups to participate.

1. The purpose of the taskforce has to be crystal clear - a demanding common task builds community
2. Time is needed to build trust, and participation should also be time bound
3. The task force should reflect the area’s diversity and bring them together around a common cause
4. Community connectors are vital to the task force as they’re motivated and ‘reach’ into their networks
5. The experience needs to respect patient stories and take into account their needs and energy levels
6. Experience is everything: Need for attention to detail, to demonstrate care, to make it unique
7. Ongoing communication and feedback is needed. Action needs to be demonstrated.
8. Everyone is equal - need to create conditions that ensure all voices are welcomed and listened to
9. The task force will work best when it becomes a community with peer support and learning
10. Meet people where they’re at - on their terms, in ways that suit them, on things they care about

**WE ARE MACMILLAN. CANCER SUPPORT**
Top tips for designing participation – Do!

1. Do take time to get to know your participants. Good relationships are important in the long term and can support the sustainability of the work you’re doing.

2. Do spend time before an event understanding what will make attendance worthwhile for the participants. What do they want to get out of the event? What would make them come back again? How do their needs match with your expectations?

3. Do build in time to allow participants to get to know one another and tell their stories.

4. Do consider the energy levels of your participants. If fatigue is likely to be an issue, think about later start times, shorter days, or allowing people to leave early (without feeling bad!).

5. Do hold events at non-traditional venues. Rather than a meeting room, could you meet in a cafe, social enterprise space, or another type of venue with an interesting history?

6. Do create a welcoming atmosphere. How you run the event is as important as where you have it. Try to ensure that everyone attending gets a personal welcome and is introduced to another participant at the start, so they don’t feel lost. Small details add up!

7. Do have fun! You’ll have objectives for your work, but you’re more likely to achieve them if everyone who attends has a good time as well as contributing to a larger piece of work.

8. Do help people visually identify different roles in the group - we used badges with M for Macmillan staff and as an example (people had initially thought we might be Macmillan Nurses!)

9. Do thank everyone for attending. You can do this on the day (e.g. by providing a small gift or something to take away) but also the next day via email.

10. Do follow up and collect feedback as soon as possible after the event (ideally within one week).

11. Do share the feedback with participants so that they know you’ve listened to them.

12. Do provide participants with regular updates on how work is progressing.

For more information visit: www.macmillan.org.uk
Five steps to ensure people in your community have their say

1. Set out the case for change so people understand the current situation and why things may need to be done differently

2. Involve people from the start in coming up with potential solutions

3. Understand who in your community will be affected by your proposals and find out what they think

4. Give people enough time to consider the plans and provide feedback

5. Explain how you used people’s feedback, the difference it made to the plans and how the impact of the changes will be monitored

Found at: www.healthwatch.co.uk/reports/5-things-communities-should-expect-getting-involved