

EVALUATION OF THE EXPERIENCE LED COMMISSIONING FOR END OF LIFE CARE PROJECT

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Experience Led Commissioning for End of Life Care: Final Evaluation Report

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The experience led commissioning evaluation was conducted from March to December 2011. For more information about the evaluation contact:

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Executive summary

Background Two priorities of NHS reform are (1) to commission and deliver services that are more user-centred, and (2) to develop clinical commissioning. Experience led commissioning (ELC) is a new way of doing commissioning that involves the use of person-centred planning processes and builds on experience-based co-design. It also includes patient perspectives drawn from a secondary analysis of a national data archive of health experience that has been systematically collected and analysed by the University of Oxford's *Health Experience Research Group* (HERG). More specifically, ELC involves patients, carers and frontline staff co-designing a commissioning strategy and service across facilitated workshops. ELC incorporates insights from patient experience (local and national) across all stages of the commissioning cycle. This document presents the results of an evaluation of the Department of Health funded ELC pilot in end of life care.

Methods Data for the evaluation were collected using qualitative methods. Data included interviews with 15 key stakeholders involved in the ELC project, interviews with two representatives from a Clinical Commissioning Group (CCG) who were acting as a 'control group', a secondary analysis of 11 patient/carer interviews conducted by the ELC team, the use of ELC literature, and finally researcher observations of four ELC events.

Key findings

- ∞ Participants reported that ELC events were well organised, professionally delivered, engaging and well facilitated.
- ∞ ELC events were thought to be well attended by a range of relevant stakeholders, including users (patients and carers), GPs/clinical commissioners, managers, frontline health professionals, user representatives and service providers.
- ∞ It was agreed that ELC events supplemented national patient experience data with local experience, identified local assets, engaged stakeholders, and created a sense of enthusiasm and commitment to improve end of life care.
- ∞ The synergy of ELC events, activities and trigger films of patient and carer experiences was noteworthy. It was found that trigger films were powerful and facilitated discussion on end of life experiences when used as part of the ELC process. However, the ELC process and trigger films go hand-in-hand, and results from the control group suggested it is not enough to provide CCGs with trigger films to use on their own.
- ∞ Data also highlighted the generation of user feelings (e.g. bringing back memories of difficult experiences, anger about current services) and expectations that need to be skilfully managed in terms of caring for users and sustaining on-going commitment.
- ∞ The ELC commissioning process was thought to be different from the usual way of doing things because it was seen as more 'human' and 'real', involved 'meaningful' user engagement, contributions from a wide range of stakeholders, and was run as a change management process.

- ∞ The particular needs of user groups that services are being designed for should be taken into account, and options for user contribution designed accordingly. For example, if it is likely that the user group will find it difficult to attend events, ELC facilitators should provide options that allow users to contribute (e.g. additional transport options, assist users to participate from home).
- ∞ Care needs to be taken that users are not sometimes overshadowed by clinicians perceived as 'powerful' at events, or that staff feel they cannot contribute some observations for fear of offending users.
- ∞ Reported outcomes from the pilot were wide ranging and included: an end of life commissioning strategy document; a health needs assessment and management action plan for *Healthworks*; a web-based interactive case study; identification and recruitment of 'change champions' to facilitate implementation of the strategy; a map of local assets for improving end of life services; increased learning (e.g. more understanding of users' needs at end of life, how ELC can be run more effectively in the future); information sharing and networking; establishment of electronic resources; and an increased national profile for ELC.
- ∞ The evaluation found that developing a commissioning strategy using direct participant experiences and engaging relevant stakeholders is a complex process, and these challenges were met in the current project. However, the same level of thought, skill and dedication will be needed in the next phase of implementation; and expectations generated in the first phase need to be managed in future phases.
- ∞ The complexity of commissioning, potential costs involved, and changing cultures and mindsets were all considered potential barriers to changing things in the implementation phases.
- ∞ Increased costs were not considered inevitable by commissioners, as user preferences (e.g. reduced hospital admissions) could actually save money in the long-run, yet cost implications need to be investigated in future research, especially since the current language and logic of ELC might not automatically make sense to commissioners.
- ∞ GPs pointed out that services co-designed using ELC are likely to get patient approval, and it makes sense that services should be built from the consumer upwards.
- ∞ Facilitation, expert change management, and evaluation of subsequent implementation phases will be important. Future evaluations need to consider issues like impacts, feasibility, acceptability, complex organisational change issues, as well as answering important questions on cost implications.

Conclusions The ELC pilot in end of life care has resulted in the development of a new end of life commissioning strategy for *Healthworks CCG*. Overall, the evaluation was favourable about the delivery of ELC, highlighting some process issues that will require attention in moving into the next phase, and when delivering future ELC projects.

Background

Experience led commissioning (ELC) is a commissioning process that has been developed by *Georgina Craig Associates (GC Associates)* with input and advice from the University of Oxford's *Health Experience Research Group (HERG)*, as well as Glen Robert from Kings College, London. ELC provides a new way of using patient experience as an integral part of clinical commissioning in the NHS. The aim of ELC is to put people at the centre of clinical commissioning by using "robust patient experience insights and co-design" in a systematic way. ELC is relevant to the current movement within the NHS towards a more user-centred service, where the Government is keen that any modernisation of the NHS involves putting patients "at the centre of everything the NHS does" [1] by giving them more choice and control. The recent Government White Paper has stated that this change will be achieved using the principle "no decisions about me without me", and that services will be designed around users, rather than expecting users to fit into services [2].

ELC combines a number of person-centred approaches (e.g. social marketing, social movement theory, PATH (Planning Alternative Tomorrows with Hope) exercise, The Esther Project)[3], and draws heavily on the principles and practice of Experience Based Co-Design (EBCD) which was developed by Paul Bate and Glen Robert[4-5]. Up until now, EBCD has mainly been applied in secondary care, and as an improvement process with service providers. EBCD brings users and staff together to improve and redesign services. It focuses on capturing and understanding staff and user experiences of the service, placing a particular emphasis on personal feelings which are captured by patients 'telling their story'[6]. ELC brings EBCD principles and other person-centred approaches into commissioning, and combines them with the use of the highest level of user qualitative evidence: namely a national collection of over 2500 health experience interviews collected by HERG at the *University of Oxford*. Existing archives of user experiences are subject to secondary analysis by the HERG team at the *University of Oxford* for ELC purposes. In order to develop an ELC commissioning strategy, national data are combined with local views and 'traditional' commissioning data sets (e.g. public health and service use) to better understand local need and experience. At the local level, broad data for ELC are gathered from a sample of local participants (including service users, frontline medical staff, GP commissioners and service providers). In addition to collecting local views, to aid implementation of the ELC strategy, local events also aim to identify solutions and local assets, and create a sense of ownership and commitment to the ELC strategy, as well as momentum and energy for change. *Pathfinder Healthcare Developments Community Interest Company* was the local project delivery partner in this work; they facilitated introductions to local organisations, suggested people who *GC Associates* should talk to, undertook local project management, and co-facilitated an ELC event. More details on the ELC approach and its theoretical background can be found in Appendix 1, in the ELC 'think piece': Putting people at the centre of clinical commissioning: experience led commissioning [7], and at <http://www.experienceledcare.co.uk/>.

In 2011, funded by the *Department of Health*, ELC was piloted for end of life care services within the *Healthworks Clinical Commissioning Group (CCG)*, which covers part of *NHS Sandwell and Heart of Birmingham PCT*. This pilot involved a series of five local events held at a location in the centre of Birmingham (Table 1 and Appendix 2). Events were attended by local users (users and carers using end of life services), user representatives, GP commissioners, service providers and other health

professionals with an interest in end of life care. This report presents the results of an evaluation of this pilot project conducted and funded independently by the University of Westminster.

Table 1 – Events for the experience led commissioning for end of life care project

Event	Dates	Description
Co-Design Events		
Co-Design Events	10 th May & 25 th May	Predominately for local users (patients and carers) and user representatives to express their experiences and views of end of life services. 24 and 22 attendees, respectively
<i>Healthworks</i> Provider Engagement and Service Design Event	21 st June	Attended by health professionals and users. An end of life service design event utilizing information gathered at co-design and task and finish group events. 55 attendees
Pledge and Design Event[8]	8 th September	Facilitated workshop to find solutions to implementation challenges identified by the ELC process and engage local people to pledge their support in making change and improvement. 50+ attendees
Improvement Contract Co-design Event	20 th September	Co-design event for the provider community. 35 attendees
Management meetings		
Task and Finish Group	25 th March, 10 th May, 13 th June & 20 th September	For local health professionals. Project planning meetings to oversee the ELC process, create clinical champions and bring together community assets.
Implementation planning meeting	31 st August	Meeting with <i>Healthworks</i> clinical leads and users regarding the draft end of life commissioning strategy developed from ELC events.
Board presentation	1 st November	Board meeting when the commissioning strategy and management action plan were signed off.

Evaluation methods

Overview Data for the evaluation were collected using qualitative methods from a number of sources including interviews (with key stakeholders who were involved in the *Healthworks* ELC for end of life care project and a control group who did not take part in ELC), secondary analysis of interview data collected by the ELC team, researcher (AC) observations of ELC events, and ELC documents.

Sampling Interview participants were recruited from ELC events using convenience sampling. 15 key stakeholders (users, carers, GP commissioners, health professionals, service providers, and those designing and delivering ELC) who were involved in the ELC for end of life care project and had attended at least one event, or were involved in developing ELC, were interviewed. For the 'control group', it had initially been agreed that five representatives would be interviewed. However, at the time of the interviews only two representatives were available for interview, owing to time constraints among potential participants.

Data collection ELC Participants were interviewed by a member of the evaluation team at ELC events (9), by telephone (5), or by face-to-face interview elsewhere (1). A comparable CCG was recruited as a control group with which to help better understand the impact of the ELC process. The control CCG had end of life as a commissioning priority and focused on developing new approaches to public and patient engagement within commissioning. The control group were provided with a briefing document explaining their role in the evaluation, an end of life 'Trigger Film' used at ELC events (see Box 1), and a 'think piece' on ELC. They were also encouraged to use publically available patient experience narratives on end of life care, available at www.healthtalkonline.org and www.youthhealthtalk.org. Representatives from the control CCG were interviewed by telephone. All ELC and control interviews were between 10 to 90 minutes long, and were conducted using a semi-structured approach. The interview schedule aimed to elicit participant views and experiences of ELC (ELC participants) or specific resources themselves (control group). See Appendix 3 for the interview schedule.

The ELC team conducted 11 interviews with users which informed the needs assessment produced as part of the ELC process. These interviews were subject to secondary analysis by the evaluation team for information relating to user views and experiences of ELC. ELC documents and information were provided by GC Associates (Appendix 4). Researcher observations of events included a task and finish group, a co-design event, the engagement and service design event, and the pledge and design event.

Data analysis Interviews were typed up verbatim by a professional transcriber, and the data were analysed using thematic analysis [9]. The first author immersed herself in the data to develop an initial list of themes/codes, which was then debated with the second author to arrive at a final coding list. The first author coded all the data. Data were inputted, coded and explored in the qualitative data analysis software environment, NVivo [10]. All data were assembled into themes, and full reports on themes were analysed and debated, in order to explain all the data. Typical quotes are used to illustrate findings. The role of the person making the quote (e.g. user, GP) is not stated in order to preserve participant anonymity. Data from researcher observations of ELC events and ELC documents were predominantly used as background information for the report, and to set

the evaluation findings in context. Both authors developed a structure for the report, the first author drafted an initial write-up, which was then critiqued, elaborated on and edited by the second author. Key stakeholders also commented on an early draft before the final draft was arrived at.

Findings

Evaluation findings are presented under the following headings: The process of experience led commissioning for end of life care; Outcomes; Commissioners using experience led commissioning; What happens next?; and Recommendations.

The process of experience led commissioning for end of life care

The ELC process involved a number of events, described in Table 1 and Appendix 2. The trigger film (see Box 1) was shown at the beginning of all ELC events (including the first Task and Finish Group) as a way of focusing participants on people's lived experiences and facilitating discussions. Co-Design events involved a number of activities to illicit users' experiences, feelings and views including group discussions, group and individual tasks (Box 2), and videoed interviews with individual users regarding their experiences. The Provider Engagement and Service Design event predominantly focussed around a Planning Alternative Tomorrows with Hope (PATH) exercise. Here, the whole group designed end of life services for the local area using a 'blue skies thinking' approach (Box 2). Management meetings followed a simple format, with the purpose of overseeing the ELC process.

Box 1 - The Trigger Film
The Trigger Film is central to the ELC process; it shows a series of short video clips of real patients talking about their actual experiences of end of life care. It was developed for the ELC project by researchers at Oxford University using the Healthtalkonline data.

Participants agreed that the ELC events had been well organised and professionally delivered. Participants felt that what was planned had been well explained in advance, and that actual events had been well facilitated. Moreover, participants noted that events were energetic with high levels of participation and enthusiasm from attendees.

"Normally I get bored and ... I drop off to sleep. But I didn't. You know, so she [the facilitator] must be doing something right." P11

"There's lots of take up and interest and energy there ... I have also seen some very effective facilitators doing their jobs." P3

In addition, participants reported that they had liked the activities and exercises used. A number of participants praised specific activities, like the PATH exercise [11] and Post-It note exercise. One participant felt that writing thank you letters was an important exercise. Another reported that they felt the 'Jack and Jill' concept (Box 2) forced people to engage with issues at a personal level, and so was a good way to bring real life issues into the discussion. Another participant reported that

hearing users speak (trigger film or in person) was more powerful than seeing it written down. There were no criticisms of specific exercises / activities.

“Starting off with blue skies thinking and then working backwards is, it’s a different way of doing it and I feel like it does make you think, and having a roomful of people, because everybody then brings their ideas, so it gives you a bigger picture, if you like. So that has been helpful. ... She’s steered it so that you keep looking at the positive, so I think that’s been quite helpful, very helpful actually.” P5

“They’re good, because you could see what people actually felt, when they put their notes on the board, you know, because you think, ‘oh I never thought about that. Or I never thought about that’. So I think that was good.” P11

Participants in ELC also praised the use of the trigger film within the ELC process and were struck by the impact of incorporating user feelings via trigger films and discussions into the proceedings. The non-ELC control group opinions of the trigger film were not so favourable (see Box 3), suggesting that the trigger films are important as a *component* of the ELC process.

Users’ overall experiences of ELC were reported as predominantly positive. Many were clearly pleased to be involved in ELC events with opportunities to put their point of view across. Participants described the ELC process as ‘interesting’ and ‘good.’ Some felt that the ideas discussed at events matched their own; others highlighted the importance of people listening to the views of others.

“Yes, I think it’s good, and very interesting, I hope it works.” P11

Box 2 – Examples of ELC activities

PATH map – planning exercise that starts with the group identifying what the ideal end of life service would look like using ‘**blue skies thinking**’. A time-lined action plan is then created to achieve this, working backwards from the ideal service to what needs to be done now.

People required to make the plan happen are also identified [11].

Emotional mapping exercise – participant feelings through the end of life journey are mapped by participants writing their feelings onto post-it notes and sticking them onto a ‘map’ of the end of life journey, to show how they were feeling at each stage of the end of life journey.

Jack and Jill – are a fictitious couple using end of life services. They were developed with the ELC co-design team then used when designing end of life services using ELC. They are used as a concept to focus ELC participants at the people level; participants are urged to think what ‘Jack and Jill’s’ experiences should look like.

Thank you letters – users were asked to imagine what a good end of life experience would be like for them or someone they had cared for, then to describe it by writing a thank you letter to the staff that had provided it.

Users reported that it was reassuring to hear other users describe similar experiences and opinions to their own, and it made them realise that they were not alone with their thoughts and feelings. A key finding that emerged from the analysis was just how emotionally invested users were in ELC and its objectives of improving end of life care.

“I come out of the GP surgery and think is it me?! Am I asking too much?! But after speaking to people here today, it’s not me, definitely not me, a lot of people feel the same, and it been brilliant to come here and find them. I was dubious about coming as I’ve never been to anything like this, but I’m really glad I’ve done it.” P12

Participants felt that the events had been well designed to facilitate take up by GPs and commissioners; this included the venue chosen and the fact that the event organisers used and understood ‘commissioning language’. One participant praised the high attendance at ELC events, which they felt would have been particularly hard to achieve given that the current changes happening in the NHS meant that people were under a lot of pressure at work.

“I think that they’ve done a really good job here to get all the people together that they have done, and for this to be the third in a series and to achieve that. Because I have seen in many places that once everything’s in flux and whilst people feel under pressure and they’ve got so many things to do, that it’s actually quite difficult to get people to come together that’s over and above what their day job is.” P13

Many participants said that ELC events had identified local assets and local needs for end of life care, complementing the national database of user experiences. This was in contrast to the control group who only viewed the trigger films. These non-ELC users felt that although the trigger films covered a fairly wide spread of issues, alone they did not fully identify local needs because films did not reflect their local ethnic mix or their specific end of life needs.

“I think that ethnically, it wasn’t terribly diverse the film. And it seemed to have, in inverted commas, a white middle class perspective of end of life care.” P17

“I think, you know one of our things here is, one in nine patients here are Jewish.” P16

Participants at events in Birmingham also felt that local events had created a feeling of ownership of the new end of life strategy in the local community. These factors are discussed in further detail in the ‘Outcomes’ and ‘Commissioners using experience led commissioning’ sections.

In terms of improving ELC, a variety of participants believed that users of end of life care could be even further represented at events. Participants here noted that it can be especially difficult for users at the end of their lives to attend events (e.g. due to medication side-effects). Additionally, length of events and venue location (e.g. not being close enough to public transport) could deter user attendance. It was suggested that increased options for users to contribute if they were not well enough to attend could include participation at home by teleconferencing, Skype video, online survey or by written submission. It was also said that some professionals are unable to attend such events because of work commitments (all events were in the daytime), and that finding ways for more staff to participate (e.g. evening events) could be useful. Combining both users and health professionals was considered of great value for ELC. Generally it was said that combined events

created an atmosphere that broke down barriers between health professionals and users, and people were able to express their views.

“Everybody spoke to you, it wasn’t all, he’s a doctor, you can’t talk to him, nothing like that. ... Everybody took part, once I get talking I’m ok, it’s getting me started and I forget things you know, you feel embarrassed. But everybody took part, the doctors and the nurses and also the care workers, just to say how they felt and everything. And I thought that was really good.” P11

Box 3 – Opinions on the Trigger Film

- ∞ Helps users to feel comfortable speaking about their experiences
- ∞ Focuses participants and gives them a common dialogue
- ∞ Brings people into their feelings
- ∞ “Real”
- ∞ Increases motivation to contribute at events
- ∞ Good for understanding the small things that really help people
- ∞ Important for listening to people’s stories

“Compelling. What was so powerful was that, not only were the people talking to us on the screen, some of them were sitting in the room, but it was real. It was exactly the same for me so there’s a lot of resonance. And, and I hope that those messages will really resonate with the healthcare professionals.” P13

Those designing the service felt that the mix of good and bad experiences talked about on the film may need some adjustment for future ELC projects.

One user reported enjoying being on the trigger film that used videos of ELC participants’ stories and was shown at one of the events.

Control group (non-ELC) views of the trigger film were less favourable:

- ∞ Difficult to convert the patient experiences to effective commissioning decisions
- ∞ Not long enough to create an emotional connection
- ∞ Served only as a “reminder” to what they already knew
- ∞ Potentially patronising to GPs who hear and discuss patient narratives regularly
- ∞ Maybe more useful to non-clinicians with less patient contact

However, the analysis uncovered some tensions in the approaches of users and professionals. There were concerns that health professionals could potentially 'overshadow' users, or that users might feel uncomfortable or unable to fully express their views in some situations. Conversely, some health professionals felt that they could not speak as freely as they might have liked on some occasions, for fear of offending users. It was suggested that in addition to the combined group work, more opportunities for break-out groups that separated health professionals and users may be a useful addition to events.

"Or that we went off into separate workshop streams within the same event, it got us together as a forum but then took each group off and went, really tell us like it is." P1

There were other tensions to balance. Participants remarked on how 'very nice' and 'smart' the venue was. However, some participants believed the venue was more geared to health professional, rather than user needs. This was because it was not based in a community setting (e.g. a local hall) and so was difficult to access by public transport. However, one participant who worked with patients in the community believed that this needed to be the case in order to get the professional buy in, which was essential to the success of ELC. There were some concerns about the time commitment and complexity of ELC. Some participants questioned whether ELC could be streamlined by comprising fewer local events. However, other participants felt the number of events that had been held were necessary for ELC to be effective. One participant said that although designing a commissioning strategy using ELC would require fewer hours than are required when commissioning in the usual way, ELC does require more time input from people who did not usually spend time commissioning, therefore it could be perceived as more time consuming.

"It takes more effort, it takes more time, but I think it's the only way to do it if, if you really are genuinely going to allow people to state their views and also show that their views are taken into account." P14

The high level of user commitment to ELC for end of life care was perceived as positive, as it was considered vital to ELC to have committed users. However, the analysis highlighted the emotions and particular vulnerabilities that are inevitable in generating user commitment in serious health conditions. That is, there was a flipside to the power of engaging personal narrative and creating emotional investment in improving end of life care. By their very nature, the ELC events themselves could trigger emotions, for users as well as professionals, and this was generally seen as a good thing. Nevertheless, some carers, for instance, found that being involved in ELC brought back difficult feelings about their experiences. Other carers found it hard to hear negative and traumatic patient experiences, or felt angry and frustrated that end of life services were not improving fast enough, and that users were still experiencing issues they felt should have been resolved a long time ago. In addition, after negative experiences of end of life care previously, some users had developed relatively high hopes that ELC could improve things for end of life care in the future. Thus, there is a risk of disappointment if the implementation phases of ELC for end of life do not deliver on expectations generated.

"It's a general feeling of frustration ... nothing is changing out there, and I get angry about that. ... We all just talk around the table and there's nothing wrong with the people who are doing the talking, but when you actually get out there, nothing is changing." P10

One user felt that expectations could be partly managed by keeping users updated of progress that had been made in taking the strategy forward. It was also important to users to see that facilitators genuinely wanted to hear their views and improve end of life services.

The role of *GC Associates* in ELC for end of life was to facilitate it by organising events, keeping the momentum going, making sure things happen, and conducting analysis of the experiences being generated in ELC behind the scenes. One of the questions that has arisen is, for future ELC projects, how much does this facilitation role need to be done by an external company (e.g. *GC Associates*), and how much of it can commissioners manage themselves? The analysis we have completed suggests that facilitation, managing emotions, motivating participants and organising the ELC process is a highly skilled process. Indeed, data from the control group suggest that competing priorities (CCGs are still in their early stages of formation) may make it difficult for others to dedicate the amount of time and skill required to develop a commissioning strategy using ELC.

Despite the use of national user experience data, a few health professionals debated the representativeness of user experience at the events. Some felt that user views gained at events may offer a skewed picture of local end of life services, by only offering the views and experiences of those users in attendance who may not have had a typical experience of end of life care. Another participant with experience of user involvement felt that although there may not be all local groups represented at ELC events, many users would be hard to access and would never attend such an event. In practice, however, he felt that the user attendees were likely to be the best achievable.

"I think what we've got is the best to get ... the more disempowered you are, so some Bangladeshi women in middle of Tipton, you're never going to get to them here are you." P4

One of the challenges for facilitators during ELC events was to move people away from how they were used to doing things, towards the ELC way of doing things. For example, some lay representatives were used to talking about problems and not solutions. Part of the role of facilitators was to shift people out of this mindset towards a solution focused approach. In addition, attendees were not used to being asked to contribute to commissioning strategies. In an analysis of reasons as to why people attended the pledge and design event, 43% said they were there to learn about commissioning intentions and only 23% said they were there to contribute[3], despite the invitation clearly stating the event was about participation in the design of the strategy. One participant felt that, during a brain-storming exercise, health professionals were overly negative about what was achievable because their mindsets were focused on what NHS was able to provide. They were not necessarily considering other organisations that the NHS could work with to achieve some of the goals.

"One of them actually said ... 'you're putting me into problem solving mode, I'm not used to being in problem solving mode at these kinds of meetings.'" P15.

“Nurses, doctors saying ‘oh you can't do that, that wouldn't work ... this is an absolute wacky idea, this is a really blue sky idea, this can't happen.’ And actually I think with just minimal challenge back, it was like, well why not? People were still talking between health and social care and they were almost seeing that as the finite list of providers, or people who were involved. And you know, there's the third sector, there's voluntary, there's carers, there's charities, that you know, happily can work together.” P13

Two participants felt that social services needed better representation at ELC events. One participant felt that clarification was needed earlier in the process that this was an end of life care strategy for adults not children.

Outcomes

There was a range of outcomes as a result of ELC events, some of which could not be anticipated at the outset. Outcomes included an end of life commissioning strategy document; a health needs assessment and management action plan for *Healthworks*; a web-based interactive case study; identification and recruitment of ‘change champions’ to facilitate implementation of the strategy; and a map of local assets for improving end of life services. The process also produced increased learning (e.g. more understanding of users’ needs at end of life, how ELC can be run more effectively in the future); information sharing and networking; electronic resources; and an increased national profile for ELC that could help to support its take-up in the future. Bringing together people from different areas with the same interest also had some wider benefits, including discussion of a taboo topic – death and dying; the forming of partnerships to submit funding bids; and progressing user involvement in service design as a way of working (Table 2). There were no reported outcomes from the control group who viewed the ELC trigger films and resources.

Table 2 – Outcomes of ELC for end of life care and illustrative quotes from participants

Outcome	Illustrative quotes and additional information
Increased understanding amongst some professionals of the experiences and perceptions of users in their area of work and of other professionals’ roles. Increased understanding of one user of others feelings.	<i>“I think it's been really helpful for me to hear people's views in an environment where they're not being influenced by the fact that I'm the professional delivering care to them.” P3</i>
Health professionals and services providers gained validation and a greater understanding of what users considered good practice.	<i>“Everything is a learning experience, everything you can think yes I already do that, that's great, I'll carry on doing that, I'm really pleased I do that because that obviously is perceived as being good.” P1</i>
Networking and sharing amongst users of information, resources and sources of support.	<i>“I've been battling this for weeks and weeks and just one lady at this seminar has told me of an organization that, in all probability, can help me.” P8</i>

Networking opportunity for professionals.	<i>"It's been really good because it's put me in touch with service leaders around as well, so it's been a really good networking thing for me." P1</i>
Useful learning experience for those delivering ELC regarding: <ol style="list-style-type: none"> 1. The resources (time, money) required for ELC projects. 2. How to run future ELC projects more effectively e.g. what sort of problems may arise and thus develop solutions on how to deal with them, what exercises are useful and which need altering. 3. Ways in which ELC could be taken forward. 	<i>"I think one of the ways in which I am looking to develop the Programme moving forward is being able to understand what are the sort of ten questions that I need to ask of the commissioning community or whoever's doing the data crunching, to give me a really good insight into what's happening within those communities ... the PATH planning process with the big picture, I think probably for future events we may not go all the way to doing something like that, we might have a hybrid of it somehow." P15</i>
Undertaking of a piece of commissioning work by a CCG, resulting in the development of a strategy for end of life care designed with local users for <i>Healthworks CCG</i> .	On the 1 st November 2011 the <i>Healthworks</i> end of life care commissioning strategy was signed off by <i>Healthworks CCG</i> .
Recruitment of people who have been involved in ELC for end of life (including users) to continue to be involved by becoming 'change champions' to support the implementation of the strategy.	<i>"The workshop that I've just been in, invited those people who wanted to continue to be involved to sign up and still be there within the process." P13</i> Over 40 organisations have formally pledged to support the delivery of improved care for <i>Healthworks</i> [12].
Map of local assets.	<i>"I think they've also done extremely well at identifying local assets ... you need to know what are we doing well and what is happening which is actually really valuable that could be scaled up and made more impactful." P15</i>
ELC events created a forum for open discussion on what is often a taboo subject in this culture that stimulated a debate on death, dying and end of life care amongst some attendees.	<i>"If the people who are here and representing the wider population here are able to think and talk about subjects which have been taboo in the past, then that in itself is a model that is good." P3</i> <i>"If you haven't imagined how you want it [end of life] to be for you, then how can you help anyone else to do that?" P15</i>

<p>Development of a multimedia platform for ELC via the website and items on YouTube.</p>	<p>http://www.experienceledcare.co.uk</p> <p>http://www.youtube.com/watch?v=qeCa1yUIOio&feature=email</p> <p>http://youtu.be/J75bqsxwJPU</p>
<p>National awards</p>	<p><i>Healthworks</i> are the winners of NHS Alliance Acorn awards for best Patient and Public Involvement 2011 for ELC.</p> <p><i>Healthworks</i> are the runners up in the Patient Experience Network National Awards 2011 in the category 'Setting the stage: Building a strong foundation' for ELC.</p>
<p>Funding bids</p>	<p>As a result of getting to know each other through the ELC process, Murrayhall (a local charity), Pathfinder Healthcare Developments Community Interest Company and GC Associates jointly developed a funding bid to create person centred, co-produced services across community development and primary care for people with hypertension, obesity and mental health problems.</p>
<p>National conferences</p>	<p>Glenn Robert and Georgina Craig 'Co-designing care with patients: a new approach to PPI'. NHS Alliance Annual Conference, 1st December 2011.</p> <p>Debra Sprague and Georgina Craig 'Integrated commissioning in end of life care: the South West Birmingham experience'. The Commissioning Show, 26th June 2012.</p> <p>Niti Pall 'An NHS for patients: Making clinical commissioning work'. Reform, 26th October 2011.</p>
<p>Development of a work programme around improving people's experiences of care homes that will reshape the local QIPP programme on care homes. This is important for end of life care because approximately 50% of people who are admitted to care homes die within the first year.</p>	<p><i>"It's going to be about bringing together a group of interested people to start to redesign the care experience, the NHS care experience, within care homes."</i> P15</p>

<p>Moving forward user involvement in service design as a way of working.</p> <p>A number of professionals working with the NHS were already extremely committed to user involvement in service design and already worked in this way. These professionals were very pleased that the NHS was using this method, enjoyed meeting others committed to using this method, and felt ELC would stimulate more user-involvement in the future.</p>	<p><i>“It has really, really given me hope that the NHS is going down this approach and route. ... Certainly it will reinforce, I think certainly the approach that we’ve put forward in bids, which is very much around the patient and carer, and mobilizing services around a need to look at outcome.” P13</i></p> <p><i>“It’s really nice to come together and make the connections with those other people. Because it gives you a sense that you know, culturally, this is being driven forward by a lot of people in a lot of different places. And that’s quite motivating actually, it sort of keeps you going.” P14</i></p>
<p>ELC as a vehicle for organisational development</p>	<p>The ELC project manager has been asked to prepare a paper for <i>Healthworks</i> about how it can use ELC as a tool for organisational development, and as a part of its CCG development planning process.</p>
<p>Improved collaboration between <i>Healthworks</i> and local hospices and charities looking to improve end of life care</p>	<p>A Chief executive of St Marys Hospice will lead one of the improvement work streams (see section ‘What happens next?/the future’). At an event hosted by the West Midland hospices in December 2011, <i>Healthworks</i> strategy was presented as a key regional piece of best practice.</p>
<p>Raising the profile of ELC</p>	<p>The pilot of end of life care has generated interest from organisations including Marie Curie, National Council for Palliative Care (and the Dying Matters campaign) and My Home Life. It has also generated interest from other CCGs in working with ELC in the future. See section ‘What happens next?/the future’.</p>

Commissioners using experience led commissioning

Commissioners interviewed agreed that ELC was different to the usual ways of working. Commissioners were struck by the range of stakeholders involved in ELC, including the number of users involved and the extent of their involvement. Some commissioners said that in the usual commissioning process user engagement often felt ‘tokenistic’ and was conducted for the sake of ‘ticking a box’ rather than meaningful engagement. ELC was also described as different to the usual way of commissioning due to the extent of other stakeholder involvement in ELC e.g. frontline medical staff and those working in the community. Other differences included the emphasis ELC placed on understanding user feelings, rather than commissioning being more an intellectual

process. Commissioners felt that ELC had allowed them to listen to the lived experience of users which made it feel like a more 'human' and 'real' way of commissioning.

"A PPI person or a committee or a reference group or a, you know, patient participation group, because that is not really going to achieve two for the price of one, you know, it will achieve your tick box, I've done PPI, if people say and accept that that's going to tick the box. But what it won't do is it won't really help you to walk in the shoes of people who ... you're commissioning the service for." P15

"What I've noticed is that the contributions come from that range of people just, just make the, the outputs so much richer than the more limited, you know little clinical meeting, commissioning meetings that I've been to in the past ... If you look at the clinical model and the medical model and do lots of intellectual work around that, and yet really what matters to people is the care that they feel at certain points in a patient journey. And I think that's what this does, this is different. And I think it's going to bring, you know, really some different results" P14

Another way in which ELC differed to the usual way of commissioning was that ELC was run as a change management process, which generated a motivation among event attendees to change things in end of life care.

"I felt an energy and inspiration in the room. I felt a desire to get things done. So that, that was very good and in my experience of, in previous commissioning groups, I don't think there was the same energy and buzz." P13

Some participants felt that involving users in this way could improve services by making users feel more listened to and cared for. One commissioner hoped that commissioning in this way would result in the provision of services that were not diagnosis based, but suitable for all those at end of life regardless of their diagnosis e.g. support with logistical issues faced by all carers such as obtaining a death certificate. Another Commissioner hoped that commissioning this way would provide services that held 'greater face value' to patients. With the role of commissioning likely to shift to GPs, one GP commissioner felt that GPs would be perceived by patients as more directly accountable for the services/lack of services available. When justifying service provision to patients it was felt that being able to tell users that services had been commissioned based on the care other users said they wanted was valued by GPs. It was thought this approach could help to preserve the doctor-patient alliance as the NHS embarked on a controversial agenda of change.

"We can create services which satisfy people more and make people feel more cared for, more listened to, and often it's those areas that make the most difference to people. And I think that's where we need to improve and I think this process will help to make that happen." P14

Participants with experience of working in the private sector said that a commercial company would never design a product or service without significant input from the users of the product. It made sense to them that commissioning in this way would produce more satisfaction with end of life services.

“That was the bit that I felt was missing, it was this market research element of commissioning ... it just didn’t seem to me that commissioners, although they were in effect they are our surrogate, they’re buying things on behalf of us, the public. They didn’t seem to be very capable of walking in the shoes of the people who were actually, they were commissioning for. And I had quite a lot of concerns about the scientific value of having one person sitting on a committee, because I felt that that just wasn’t going to give you a very rounded picture.” P15

“If you aren’t around the customer then somebody will come in and provide what the customer wants and you will lose your customer.” P13

Participants identified a number of barriers and facilitators to commissioning using ELC. Facilitators included the range of stakeholders involved in the process and the commitment they expressed to working to change end of life care. User involvement in events was considered important in developing a richer, more robust strategy that would identify the needs of local users. Health professional involvement was considered important to push the strategy through. Involvement of frontline health professionals and those working in the community was important to produce a sense of ownership. This was important because many of these people would be the ones implementing the strategy, such as frontline medical staff, or with the power to make changes happen in the community. Change management theory suggests that involving key people in the change process increases the chances of successful implementation [e.g. 13].

“I think the amount of people who have got involved with this project speaks volumes really. ... Some of the patient representatives we have here are local voices and they do run community events and things, so they can get the message out. That’s the difficulty, is getting the message out now.” P12

The commitment to ELC for end of life care from the management of *Healthworks* and the local PCT was considered vital to making ELC work because the people at the top were driving the agenda and setting examples of how to work.

“The vice chair of Healthworks was passionate about it. So that helped move it forward. [The] clinical champion and the management champion helped make it happen.” P12

The commitment among health professionals and *Healthworks* management to develop an end of life commissioning strategy was particularly impressive against the current political backdrop. The NHS is currently in a state of flux with commissioning responsibilities changing from PCTs to CCGs, the exact details of which are still being debated. CCGs are currently still forming and developing, and this makes undertaking commissioning work difficult, even in an area identified as a priority. This was emphasised by the control group who were not yet ready to start thinking about commissioning strategies.

“For our CCG, it [end of life care] is one of our clinical priority areas, I think because we’re early on in our development it’s ... we’re not at the stage where we you know, we’ve actually got the ability to vote GPs and a very small number of resources to do that so it’s not a priority in the short term. In the medium to long term it will be a very large priority area.” P17

The enthusiasm among attendees, other stakeholders and members of the wider medical community was also considered an important facilitator in making the ELC process successful.

Indeed, some other research has shown that when patients and health professionals participate in projects that involve patients in service development, they become more positive in both their attitudes and actions towards patient involvement, compared with control groups who don't participate [14]. In addition, some participants felt that the involvement of researchers in the process (University of Oxford) and the independent evaluation team (University of Westminster) would be important to the success of the project.

"I think everybody put their heart and soul into it. And there's a definite will for change and a definite will to come up with a strategy that works for people. So, you know, I think, I mean, they all seem very determined to make a difference so I hope so." P9

*"I'll certainly be promoting what I've seen here today. And I hope to be involved in future events."
P13*

As well as facilitators, participants reported a number of potential barriers to ELC changing end of life services. One of the main perceived barriers was the complexity of parts of the commissioning process; it was felt that rules, regulations and bureaucracy may hinder *Healthworks* ability to commission services based on ELC findings.

"There are lots of rules around commissioning, which are sometimes European rules which we get from that area of government. Sometimes the rules are based around what would be considered to be good public body use of money. And so those rules are good rules, but occasionally you have to, when someone comes up with a good idea and actually sometimes the rules unfortunately don't facilitate the good idea coming into action easily." P2

Some also felt that there could be potential financial barriers: 'What if ELC recommendations were more costly?', was a question raised. However, a number of participants believed that this might not be the case because key things users talked about being important at end of life, such as being treated with kindness or aiming to reduce hospital admissions, could ultimately save money. Work in the USA using the "patient- and family- centred care method" has found that building and viewing care experiences through the eyes of the patient and family in orthopaedics may improve outcomes without additional costs[15]. Nevertheless, there were additional concerns that because commissioning centres around cost and clinical effectiveness, things like kindness and empathy do not fit the model, and are more difficult to measure and promote. One participant considered the lack of cost data for end of life care a barrier to ELC.

One participant had been involved in NHS end of life care for many years and claimed to be cynical about the ability of the NHS to change and improve end of life services. They reported they had witnessed the issues raised again and again, but never actually fully addressed at the level of implementation.

"Implementation is always an issue, that's not unique to this particular project, I've worked on millions and millions of initiatives over the years because I've worked in the quality sector for donkey's years. There's always something new in the pipeline and yet we seem to go round and round addressing the same old chestnuts year after year after year..." P9

Other barriers were related to changing the culture and mindsets of individuals and organisations. For example, there were concerns among some healthcare professionals, including commissioners, that qualitative data gained at ELC events may not be representative enough for the commissioning process, fitting the 'rent a quote' category, rather than the robust social science demonstrated by HERG, or indeed quantitative outcome data. Others felt that there would be a power issue where some commissioners would be resistant to the idea of handing more 'power' to patients. Another potential barrier discussed by participants was the fact that this was a new way of doing things and some people and systems would naturally be resistant to change. Some considered that the current climate within the NHS means that staff were afraid of losing their jobs and were thus particularly resistant to change. Other participants felt that any positive change in patient's end of life journey could only happen in the context of caring communities that were less afraid of death and dying than they were, and that this kind of change is beyond the remit of ELC. So for example, people at the end of life would only cease to experience isolation when people in the community did not become afraid to talk to them. Nevertheless, community attitudes to death and dying will be addressed by ELC as one of the five improvement work streams that need to be progressed to deliver change, identified in the *Healthworks* commissioning plan [12].

What happens next? / the future

At the time of publication of the evaluation there was obvious momentum behind ELC and enthusiasm for commissioning in this new way from the PCT, *Healthworks* and those who had been involved in ELC events. *Healthworks* CCG had ratified the strategy on 1st November, 2011. Funding to support implementation (outlined in the Management Action Plan) had been agreed. Responsibility for implementation of the end of life strategy will be led by *Healthworks* end of life Management Team, supported by managers from the PCT cluster. The Management Team will comprise a clinical lead to manage the implementation, a GP champion and a non-executive CCG Board member. Commissioning improvement work comprises various work streams, developed as part of the ELC strategy. Each stream will have a 'champion' who will be either a lay person, provider-based manager, or health professional recruited through ELC events. The team will receive a leadership coaching programme, delivered by *GC Associates*. This coaching aims to support people to maximise their personal effectiveness and become a cohesive group. This will include training regarding the strategy and its background, project management and skills to influence people. A group of local volunteers will also receive coaching in personal effectiveness so that they can contribute to driving change for end of life care. Progress towards improving end of life care will be monitored through improvement contract metrics, co-designed with providers. Improvement contracts will be agreed, and not necessarily linked to financial payments.

"It will be taken forward on a, a project based approach with various work streams championed by a clinical lead, supported by a group of change champions that have been drawn from the co-design team, and then with some management support at the CCG." P15

"We'll be testing that, through our contract reviews." P6

During interviews a number of people expressed a wish to see ELC for end of life care expanded. As a result of the pilot project, there was interest from other CCGs in working with ELC. There are plans to take ELC forward through a 'federation' model and through franchising. Given that *Healthworks*

had done a major piece of commissioning work in the end of life area, it was felt by some participants that *Healthworks* may be able to take the lead for end of life care amongst other CCGs, with some additional work added into the process locally. Indeed, *Sandwell and West Birmingham Clinical Commissioning Federation* is a group of four CCGs including *Healthworks*, who share the same provider base and have end of life care as one of their priorities. Currently, the Federation is in discussion with *Healthworks* and PCT cluster managers to adopt the *Healthworks* end of life strategy developed using ELC, with some additional work to check the strategy and update the needs assessment. Some participants also felt that ELC could be used to develop commissioning strategies for other areas of health, within *Healthworks* or with other CCGs. One participant suggested that such work may involve CCGs coming together from the beginning to create new commissioning strategies across CCGs using ELC.

“We can start it off and then we can learn from that. But we need to then recognise how do we, how do we take this learning to say diabetes or a COPD, asthma and that sort of thing.” P12

“If I was to predict the future I think Healthworks will go to the other CCGs in its area and it will suggest that it takes a lead on end of life care commissioning because it's been the first to do some commissioning in that way. There will be ways if we wanted to of broadening the strategy a little bit, to create at low marginal cost a co-design event in each of those CCGs. ... I think they would, they recognize that the way in which commissioning is developing that over time CCGs are going to merge and they would use ELC to help them to explore with their neighbouring CCGs how to find the right way of doing that, so commissioning together.” P15

GC Associates have proposed an ELC ‘franchise’, which would be spread by a method called ELC ‘cascade’ [16]. In short, this means that *GC Associates* want to be able to grant to CCGs licenses for the ELC approach to commissioning, including providing training for a group of people within CCGs to develop as ‘licensed practitioners in ELC’. At the time of writing, one CCG had agreed to the franchise approach. This evaluation found that expert facilitation and delivery, in order to fully engage people in a useful process, was vital to the success of developing a commissioning strategy. Thus, evaluation would be important in investigating implementation phases, including any franchise program.

Conclusions

The pilot ELC for end of life care was evaluated independently. Overall, the evaluation uncovered favourable reports on the delivery of ELC. A wide range of stakeholders said that ELC events were well organised and facilitated, and engaged people from a wide variety of backgrounds, all with interests in end of life care. Far from being ineffective, the synergy of trigger films and expertly facilitated activities was moving for participants, and created momentum for action. At ELC events there was enthusiasm generated for improving end of life care services, and a number of stakeholders had committed to working with *Healthworks CCG* to support implementation. The ELC commissioning process was considered different from the usual way of commissioning insofar as it was seen as more ‘human’ and ‘real’, and involved more meaningful engagement with a wide range of users. At the same time, the evaluation highlighted some specific issues with the ELC process

which could be addressed to further improve delivery of future projects. The range of stakeholders involved and their commitment to ELC were considered facilitators to ELC improving end of life services. Nevertheless, there were some concerns raised that the complexity of the commissioning process, cost, and changing mindsets and behaviours were potential barriers in implementation phases. At the time of writing the current evaluation report, a new end of life commissioning strategy for *Healthworks CCG* had been developed, and planning of its implementation had begun. It is intended that lay members of the co-design team, frontline health professional and local providers will be integral to implementation.

Recommendations

As a result of evaluation findings outlined in this report, the following recommendations are made for future commissioning using ELC:

- ∞ Explore streamlining the ELC process through reducing the number of stages in a single ELC project, as well as using the current end of life project to inform - or partly replace - the need for ELC in end of life care for other CCGs
- ∞ Recognise and build into ELC flexibility to accommodate the varying needs of lay contributors. Design options for involvement accordingly e.g. if it is likely that the user group will find it difficult to attend events, provide options that allow users to contribute from home
- ∞ Reflect upon the balance of positive and negative experiences shown in trigger films for future ELC projects, taking into consideration the effect that hearing very negative experiences may have upon users in particular
- ∞ During co-design events, consider including separate break-out sessions for health professionals and users to allow people to speak more freely
- ∞ Encourage health professionals attending not to wear their uniforms, in order to break down boundaries between users and health professionals
- ∞ Feedback to stakeholders changes that have happened as a result of the ELC project they have been involved in (e.g. via newsletters)
- ∞ Have confidence in the effectiveness and power of feeling and motivation generated at ELC events, but ensure facilitators are skilled in how to manage the feelings and the expectations created. The use of a patient-centred approach sets up expectations, and puts the onus on CCGs to deliver on expectations created using ELC
- ∞ Ensure venues for ELC are accessible via public transport for increased user involvement
- ∞ Ensure expert facilitation, change management strategies, and evaluation (including cost implications) continue through to implementation phases

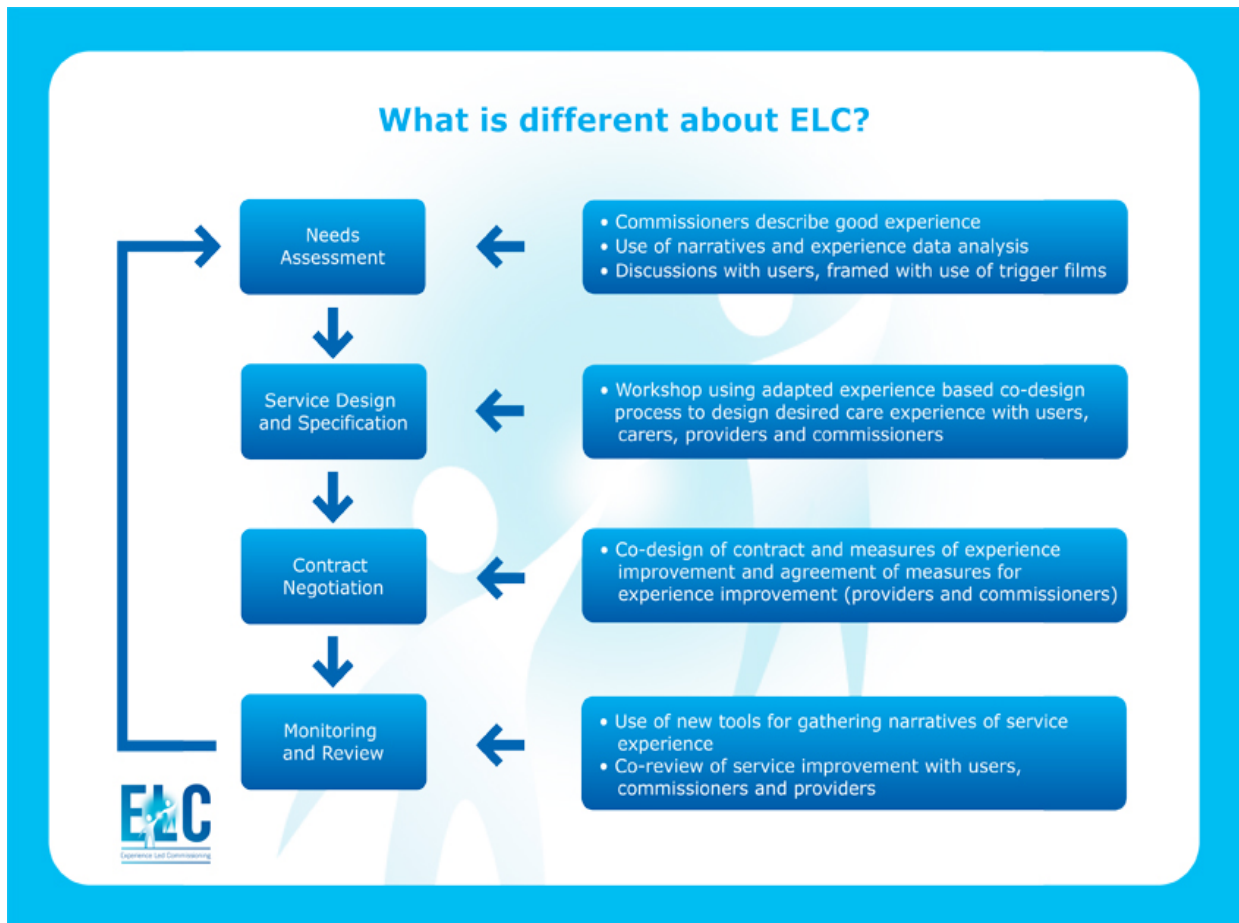
- ∞ Start with a clear definition of who the commissioning strategy is for e.g. adults or children?
- ∞ To achieve needs identified through ELC, encourage CCGs to work with external organisations, such as those in the community/voluntary sector.
- ∞ Explore how CCGs can work together using ELC to commission services in other health areas
- ∞ Document experiences, facilitators and barriers to implementing the ELC commissioning strategy for end of life care
- ∞ Future research and evaluation should seek to understand cost implications of ELC in more detail; implementation of ELC once the strategy has been ratified and handed over to the CCG; ELC using franchising; and ELC for other health areas
- ∞ Research should seek to gain a more thorough understanding of the impact of trigger films for the ELC process: e.g. how important is the trigger film to the process, and are they essential?
- ∞ The evidence from this evaluation is that the ELC process engaged patients in the commissioning process in a meaningful way and created momentum towards implementing patient-centred approaches to end of life care among a range of stakeholders. This makes ELC relevant to the current movement within the NHS towards a more user-centred service [1]. It is therefore recommended that further resources be invested in refining and researching the ELC process, included developing the implementation phases. Here, evaluation should look at issues like other health conditions, implementation processes and outcomes, the role of change and leadership in organisations, franchising, and cost effectiveness

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Appendix 1 – Description of ELC

Reproduced with the permission of GC Associates from the ELC document “Putting people at the centre of clinical commissioning”.



Appendix 2 – Details of events for the experience led commissioning for end of life care project

Co-design events	Objectives	Who was involved
<p>Defining the current end of life care experience</p> <p>MAY 2011</p>	<p>Working with a group of local people and frontline clinicians, we helped people reflect on their current experience of end of life care, using trigger films created from a national research archive of people’s experience of care available at www.healthtalkonline.org. We used EBCD methodologies to help the group create an emotional map of current experience from the staff, person and carer perspectives. We also interviewed 24 people, carers, managers and clinicians with relevant experience.</p>	<p>22 people in total. A group of 15 local people (patients and carers) with relevant experience of end of life care and primary care nurses, GPs, palliative care specialists plus commissioners.</p>
<p>Defining a good care experience</p> <p>MAY 2011</p>	<p>People were asked before the meeting to write a thank you letter to <i>Healthworks</i>, describing a great end of life experience they or someone they cared for had had. These were collected and analysed to create a word cloud. Working with the same group of local people and clinicians (our co-design team), we co-designed the care experience we want to commission in the future. Aided by an ELC trigger film of people talking about good end of life care drawn again from the National Archive, we created emotional maps of good care from the person, carer and staff perspectives. We drew learning from The Esther Project and spent time co-creating the stories of two characters - Jack and Jill - who will personify and reinforce person centred thinking within our end of life change programme through into implementation.</p>	<p>22 people in total. A group of 15 local people (patients and carers) with relevant experience of end of life care and primary care nurses, GPs, palliative care specialists plus commissioners.</p>
<p>Defining our vision of great end of life care</p> <p>JUNE/ JULY 2011</p>	<p>Over two meetings, we applied the person centred planning technique Planning Alternative Tomorrows with Hope (PATH) to commissioning. PATH is more often applied to individual person centred planning and asset based community development. PHD CIC regularly apply it to service redesign. PATH helped us to create our vision of great care in three years time and how we will get there starting from now through commissioning. To view a video that walks through our PATH to great end of life care, go to: http://youtu.be/J75bqswJPU.</p>	<p>55 people in total. Our core co-design team and clinical commissioners plus an open invitation to all local providers, third sector organisations and community groups to attend and contribute.</p>
<p>Pledge and design event</p>	<p>This event engaged all the ‘assets’ within the community – the people and organisations who can make change happen. We spent the day, asking people to work with us to problem solve the improvement challenges our strategy development work had uncovered. We then asked them to pledge to work with</p>	<p>We put an open invitation to all providers on Supply2NHS (current and future potential). Over 50 people attended from all</p>

SEPTEMBER 2011	us to improve end of life care. We gave everyone a thank you card with the word cloud as a memento. Over 30 people and organisations pledged to work with us to improve end of life care in <i>HealthWorks</i> . To view a photo album of this event, go to: http://youtu.be/gRLRHK3bdJs	the key organisations we need to engage with to make change happen plus our core co-design team and key CCG clinical commissioners
Improvement Contract co- design event NOVEMBER 2011	This event engaged the provider community in working with us to define a fair reward for great work in provision of end of life care. We asked people to co-design the metrics of improvement with us that would demonstrate to anyone who needed to know that we were progressing towards our vision of great end of life care. People worked on their chosen improvement work stream. We undertook a 360 degree appraisal of the event and the write up was circulated to all participants.	We put an open invitation to all providers on Supply2NHS (current and future potential). 35 people attended from a range of current and qualified provider organisations across the NHS, private and third sector

Management meetings	Dates	Description
Task and Finish Group	25 th March, 10 th May, 13 th June & 20 th Sept	The Task and Finish Group was set up to oversee strategy development and to engage all of the management team closely involved in the strategy development process. It included the two clinical commissioning champions for the work, alongside key managers from the PCT cluster. It was convened and secretariat provided by the ELC project manager. The team quickly grew into a larger virtual group who were kept up to date with developments by email. The key tasks of the group were to: oversee the ELC strategy process, build support and create strategy champions, and feed in and engage community assets through members' networks who could contribute to improving end of life care.
Implementation planning meeting	31 st Aug	This was a one off meeting with <i>Healthworks</i> clinical leads and users to discuss the implementation strategy for the draft end of life strategy developed from ELC events.
Board presentation	1 st November	This was the board meeting when the strategy and management action plan were signed off following a presentation by the ELC project manager.

Appendix 3 – ELC participant interview schedule

1. What was your role in the End of Life project activities?
2. In what way, if any, do you feel that the End of Life events/ activities influenced how you think or feel?

Prompt: has it changed your understanding of the experiences of patients using end of life care services and their carers?

3. How does this way of commissioning compare with the usual way that commissioning is done?
4. Do you think there will be any effect of the End of Life events on the commissioning of end of life care services? If yes, what?
5. How well do you think the events will identify local needs?
6. Are there any other ways you think the End of Life activities will influence what you do or will do in the future?
7. Can you name one or two benefits of events for end of life care services?
8. Are there any disadvantages to the End of Life events/activities that you can see?
9. What did you think about the way that the End of Life activities and workshops were put together?

Prompts: What did you think of the specific activities? What did you think of the trigger film? Which parts of the process had most impact for you? How successfully did you feel it broke down barriers between health professional and users?

10. How could the End of Life service design activities be done better?
11. What have you learnt from your involvement in the End of Life service design process?
12. Is there anything else you'd like to add regarding the End of Life project which we've not already discussed?

Appendix 4 - ELC documents and information provided by GC Associates

Path Planning end of life care HealthWorks. Available from: <http://youtu.be/J75bqsxwJPU>

Putting people at the centre of clinical commissioning: Experience Led Commissioning

Healthworks End of Life Care Pledge and Design Event. Available from:

<http://www.youtube.com/watch?v=gRLRHK3bdJs&feature=youtu.be>

360 degree feedback on Health Works End of Life Care Pledge and Design Event

Health Works Management Action Plan End of Life Care Commissioning Plan

CCG Experience Led Commissioning (ELC) Franchise

DRAFT strategy for end of life care

Briefing Herts Valley CCG - a control group in the evaluation of experience led commissioning of end of life care

Workshop plan Healthworks, co-design of end of life experience, Tuesday 10 May 2011

DRAFT Experience Led Commissioning Needs Assessment (end of life care) for Health Works GP Consortium

Experience Led Commissioning: end of life care health

Experience insights analysis for Health Works Consortium

Health Works Task and Finish Group End of Life Care ELC

Sandwell Support and Palliative Care Strategy End of Life Care Task and Finish Group 25 March (PowerPoint presentation)

Glossary

ELC	Experience led commissioning
CCG	Clinical Commissioning Group
HERG	Health Experience Research Group
GC Associates	Georgina Craig Associates
NHS	National Health Service
PATH	Planning Alternative Tomorrows with Hope (an exercise)
PPI	Public and Patient Involvement
QIPP	Quality, innovation, productivity, prevention