System transformation in palliative and end of life care

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System Transformation in Palliative and End of Life care: developing a model for excellence

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Introduction

It is estimated that 40 million people globally need palliative care services annually, yet only 14% of them receive it (World Health Organization [WHO], 2018). Global deaths in 2030 could rise to 64.9 million, (Mathers and Loncar, 2006) indicating this need is set to increase. It is predicted that the number of annual deaths in England and Wales will rise from 501,424 in 2014 to 635,814 in 2040 (Bone *et al.* 2018), an increase of 25% (ONS [Office for National Statistics] 2016, 2019; Public Health England [PHE], 2019).

Although there was an overall reduction in hospital deaths in England between 2006 and 2017 (PHE, 2019), almost half of all deaths in 2016 still occurred in hospital (46.9%) (PHE, 2018), despite this being the location where the fewest people wish to die (Gomes *et al.*, 2011). Patients continue to receive non-beneficial treatment in hospitals towards the end of their lives (Wyatt and Bennett, 2017).

These factors have combined to determine that end of life care has become a more pressing issue for UK policy-makers (Academy of Medical Sciences, 2019), and that an infrastructure across care settings to manage rising annual deaths is urgently needed (Bone *et al.* 2018). The purpose of this paper is to report how the palliative and end of life care (see table 1 for definitions of these key terms) (PEoLC) community in one region of England worked together to create a new service model to address these challenges. The members of the PEoLC Community in this setting are identified in figure 1. The paper is organised into three main sections. First the need for integration and coordination of PEoLC services is identified and approaches to system integration in PEoLC examined. Next, the approach taken in a region of England is discussed to demonstrate how the design principles of system transformation informed the development of a model for integrated PEoLC. Third, the impact of the model and need for evaluation to inform the advancement of integrated health and social care service provision are explored. Finally, conclusions about the need to learn more about this type of approach to system change by conducting comparative case studies are presented to identify how evidence concerning its impact can be gathered.

(Table 1 here)

The need for system transformation and integration in palliative and end of life care

In Birmingham and Sandwell older people are living longer with a complex mix of conditions and 54% of people die in hospital, in many cases following the distress of several urgent admissions in the last months of life (The Strategy Unit, 2017). Loneliness and social isolation are also factors that contribute to urgent admissions to hospital (BGS/RCP [British Geriatric Society/Royal College of Psychiatrists], 2019). Birmingham is ranked as the seventh most deprived local authority in the UK, and some citizens are homeless and/or live in poverty (Birmingham City Council, 2019). It has a very diverse population, the end of life needs of some marginalised communities are not being met consistently, and they have little confidence in the system (Suleman *et al.*, 2019; CQC [Care Quality Commission], 2016). These factors combined to create a situation in which health and social care in Birmingham and Solihull was sometimes fragmented and uncoordinated, leading to poor outcomes for people at the end of life (CQC, 2018).

This set of circumstances is not unique. The majority of patients globally do not have access to regional, comprehensive integrated palliative care systems, do not receive care in their preferred place of care, and experience unnecessary hospital admissions as they near the end of life (WHO 2013; Brazil, 2017; Fadhil *et al.,* 2017; Knaul *et al.,* 2018). Indeed the variability and failure of PEoLC have been highlighted in several national reports which conclude that end of life care is not coordinated around the person (CQC, 2016; Parliamentary and Health Service Ombudsman 2015; House of Commons Health Select Committee, 2015; Leadership Alliance for the Care of Dying People, 2014).

To address this deficit a number of approaches have been designed to integrate services to provide seamless care for patients and their families. For example Abel *et al.* (2018) advocate 'the new essentials model' to reshape services by coordinating specialist palliative care, generalist palliative care, compassionate communities, and the civic approach to end of life care, incorporating a public health approach built on partnership between clinical services, communities and civic institutions (Abel *et al.,* 2018). The integration of these processes and organisations (Abel *et al.,* 2018) requires action on a number of levels (Brazil, 2017). At the macro, or system level to align policies and regulatory frameworks; at the organisational (meso) level to develop appropriate structures and systems of governance; at the clinical (micro) level to coordinate care across time, place and disciplines, centred on care pathways; and normative action at all levels to develop the shared values, culture and vision necessary

to deliver integrated palliative care (Brazil, 2017). Evaluation of this approach has demonstrated that collaborative practice is valued and family care givers were satisfied with the extent accessibility, and patient centredness of the service (Bainbridge *et al.*, 2016). Although it was acknowledged that such evaluations have inherent limitations because of the widely recognised challenges of undertaking research in this area (Bainbridge *et al.*, 2016). These include 'gatekeeping' by families and staff based on assumptions of patients being 'vulnerable' thus precluding patient recruitment to studies; high levels of attrition from studies; and the difficulties involved in obtaining consent from potential research participants, particularly when levels of capacity change over the course of terminal illness (Blum et al., 2015: Krause *et al.,* 2004). Also earlier work identified there is no single best template for organising services that suit all configurations of local contextual factors and existing systems (Bainbridge *et al.*, 2011). This is perhaps unsurprising because few studies report the impact of integration and focus on perceived benefits rather than empirically derived outcomes. This lack of evidence hampers understanding of how to best integrate health systems in different contexts and for different desired outcomes (Armitage *et al.* 2009).

However there is an emerging literature on Large Scale System Transformation (LST) which indicates that although it is challenging (Söderlund, 2010), programmes often fail (Smith et al 2019; Price Waterhouse Coopers 2019) and there is no 'blueprint' for LST in complex settings (Nyström *et al.*, 2014), some success factors and key principles for LST have been recommended. For example, Janssen *et al.,* (2015) conclude that seven management principles need to be adhered to if system transformation is to be successful. These include separating innovation from implementation, having unity of command and creating incentives (Janssen *et al.,* 2015). Similarly the Health Foundation (2015) identified seven success factors for system transformation such as courageous leadership, a motivated workforce, being part of a collaborative and supportive health and social care system, and funding (The Health Foundation, 2015).   However the approach taken to large system transformation reported here was informed by the rules for system transformation developed by Best et al (2012). These are listed below and examined further in the discussion section:

1. Engage individuals at all levels in leading the change efforts-which involves designated and distributed leadership.
2. Establish feedback loops-which involves the careful identification and disclosure of the measures.

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3. Attend to history-not in a deterministic sense, rather to be sensitive to the context.
4. Engage clinicians-the role of influential clinical staff is crucial in the change process.
5. Involve patients and families. (Best *et al.*, 2012; Best *et al.* 2010)

There has long been a need for a comprehensive system of services, including in-patient services, home-care services and support services to meet the palliative care needs of patients and their families (Radbruch and Payne, 2009). In England leaders of local health and care systems, including NHS (National Health Service) regional teams, Health and Wellbeing Boards, local authorities and Clinical Commissioning Groups, have been called on to develop and deliver strategic plans to deliver good quality, equitable end of life care for everyone in their community (CQC 2016; NHS 2015). In response the PEoLC community in Birmingham and Solihull in the West Midlands of England used a range of evidence and system transformation design principles to develop a model for the system wide provision of PEoLC for adults, which was sensitive to and suitable for the specific context.

(Figure 1 here)

Approach

To develop the model of PEoLC as a basis for system transformation there was a need to include the numerous key stakeholders in a process of co-production (Hewison *et al.*, 2012). Co-production has been defined as the transcending of boundaries between communities and perspectives to form productive collaborations (Antonacopoulou, 2010), which can generate powerful synergies, and offer illuminating insights on critical contemporary issues (O'Hare *et al.*, 2010). Advocated internationally (OECD [Organisation for Economic Cooperation and Development] , 2016; NESTA [National Endowment for Science Technology and Arts], 2012), it has also been recommended as an approach to leading change in health and social care because it puts people at the centre of decision making and connects representative networks enabling the people involved to influence, shape and participate in the commissioning, planning, delivery and evaluation of services as part of a genuine partnership (NIDH [Northern Ireland Department of Health], 2018; Seale, 2016).

However the construct of co-production in healthcare presents pragmatic challenges and moral hazards (Felipe *et al.*, 2017; Batalden *et al.*, 2016). There is no single agreed approach and it is applied differently in each situation, because it is co-produced by the people involved, so a one-size fits all model is not feasible, however there are some common

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underlying principles (Spencer *et al.*, 2013; SCIE [Social Care Institute for Excellence], 2015). For example the Think Local Act National Partnership (ND) identifies six principles: recognising people as assets, building on people's capabilities, developing two-way reciprocal relationships, encouraging peer support, blurring boundaries between delivering and receiving services, and facilitating rather than delivering. An acronym for the principles is 'caring': Celebrate involvement, adaptable, resources, influence of power, needs-led, and growth (NCCMH [National Collaborating Centre for Mental Health], 2019) and NESTA (2012) lists assets, capacity, mutuality, networks, blur roles and catalysts. Although there are similarities in these sets of principles, the differences illustrate the breadth of work in this area, particularly as new lists are produced for specific settings (see Hickey *et al.*, 2018; Homeless Link, 2017; NHS England, 2016 for example). In view of this the following key principles informed the process followed to develop the model reported here. Equality, diversity, accessibility and reciprocity (SCIE, 2015). These were agreed because they encompass the principles identified earlier, and have underpinned co-production work in a range of health and social care settings (Norfolk and Suffolk NHS Foundation Trust, 2019; NDTI [National Development Team for Inclusion], ND; MIND [(MIND-for better mental health], 2017).

The process

As with the methods and principles of co-production, guidance concerning the process varies with the number of recommended steps for action ranging from four (Malby 2014) to seven (NHS England, 2016). The main focus of this paper is on the development of a model for system-wide PEoLC, and so the first two steps identified by Malby (2014) are addressed:

1. Identify and understand problems.

2. Come up with ideas for change.

The co-production process took place over a 3 year period from September 2017-February 2020. It involved 73 participants who contributed to the identification and understanding of the issues and the development of ideas for change. Eight large collaborative meetings were held, during which the challenges of system transformation, were discussed and analysed. This involved presentations from data experts, service user groups, health and social care professionals, and charities to ensure all those involved had an opportunity to share their perspectives and experiences, and have access to current evidence. Between the meetings

sub-groups worked on different elements of the system design. The co-production working party was coordinated by a palliative care consultant who worked at one of the local hospices involved (see figure one for details of the group members). This group reported to an oversight group headed by the chief executive of a hospice. The Oversight Group reported directly to the Ageing Well and Later Life Board-which was responsible for directing the Ageing Well Strategy and liaised directly with the Sustainability and Transformation Partnership [STP] Board) which ensured there was high level system wide support for the service transformation process (See figure 2). In addition 20 members of the co-production working party worked together on a systems leaders development programme to support the transformation process. This involved small groups working on elements of the design and one group designed and developed the model which was approved by the Sustainability and Transformation Partnership Board in January 2020 (see figure 3).

 (Figure 2 here)
 (Figure 3 here)

The development of the model

The outputs of the co-production working party were extensive and so a number of key outcomes, which demonstrate how the model was starting to have an impact, are presented here. One of the issues discussed at length was the overall vision. This had to take account of the local context and the implications that arise from the meaning people ascribe to the terms: Palliative Care; Supportive Care; and End of Life Care (See table 1). Having reviewed this material the vision for the system transformation was agreed as: The best possible experience at the end of life- *Where the last 1,000 days of life have as much importance as the first.* The intention was this would help inform better planning, support more positive conversations with individuals and families, and stimulate wider societal change. This entailed the identification of ten high impact changes (see figure 4) to direct action in key areas to embed the model and address national policy objectives (National Palliative and End-of-Life Care Partnership 2015), and local priorities (Birmingham and Solihull Sustainability and Transformation Partnership [STP], 2018). The alignment of the national ambitions and the changes is shown in table 2. This constitutes a 10 year programme of work to effect service transformation in end of life care.

 (Figure 4 here)

The model (figure 3) conveys how the system was redesigned to reduce unnecessary hospital admissions that add little clinical benefit, offer equitable access to services with fewer gaps in provision, and improve the urgent response process. The focus of care and support is on levels 1-3 which are more effective and responsive to individuals' needs and less resource-intensive. This supports national policy priorities for PEoLC (National Palliative & End of Life Care Partnership, 2015) and addresses local needs (Birmingham and Solihull STP, 2018) a (see table 2).

(Table 2 here)

The model (figure 3) is presented as an inverted pyramid to demonstrate that when there is support available in local communities and greater integration of, and partnership between primary care networks, and care homes is achieved (levels 1 & 2), the need for secondary and specialist care (levels 3 & 4) is reduced. The model is based on its use by the Nordstrom company, founded in 1901 as a shoe retailer which was committed to offering customers the best service, selection, quality and value. This was reflected by placing the customer at the top and the chief executive at the bottom of an inverted pyramid and this philosophy continued to permeate business planning in the company enabling it to embrace digital transformation (Padilla, 2015; Collins and Porras, 1996). It has also been used in health care to reflect the need to invert the organisational hierarchy of authority if patients' are to be the focus of service provision (Nanji *et al.*, 2013). In this application patients were situated at the top of the inverted pyramid (Nanji *et al.*, 2013), to demonstrate how the PEoLC model was different and how it would operate. The four levels of the model are now explained.

Level 1-Civic action

This involves a community development approach incorporating the contribution of people and communities in supporting people and their close persons at the end of life. This civic approach is based on a wider public health perspective, which advocates community action in the design, and implementation of palliative care (Kellehear and Sallnow, 2012) and shifts system thinking from complete reliance on existing statutory services (Abel *et al.* 2013). Community development can support a more sustainable model of PEoLC (Molina *et al.*,

2017), because it involves extended family members, friends, neighbours, volunteers and work colleagues, schools, universities, workplaces, companies, social care/community development organisations and policy makers (Flores *et al.* 2018). However its potential is not currently widely appreciated, for example the impact of the community's role in supporting grief and loss is currently underestimated (Corden and Hirst, 2013). In view of this the model incorporates a commitment to achieve the Compassionate Cities Charter which requires a community to lead change in cultural and social attitudes to death, dying, loss and caregiving and to promote a civic programme of social action to care for people with advanced chronic conditions, founded on the values of compassion, humanism, and solidarity (Gómez-Batiste *et al.*, 2018; Abel *et al.*, 2018; Kellehear, 2016; Abel and Kellehear, 2016; Kellehear, 2013). It is endorsed in the National Ambitions for Palliative and End of Life Care (2015). An Equality, Diversity and Inclusion Programme for prioritised marginalised communities (LGBTQ+ individuals and communities, homeless people, Muslim communities, people with learning difficulties) is also in development as part of level 1 activity.

Level 2 – Integrated working

Three examples of integrated working (level 2) are summarised below. One is the Enhanced Support to Care Homes programme which was tested in 3 care homes, prior to implementation in a further 30 homes. It involved workforce development for care home staff and managers focussed on falls prevention, nutrition, hydration, wound management, dementia care, and quality improvement methodologies. Along with case management for residents with complex needs or deteriorating health the aim was to reduce admissions and readmissions from residential and nursing homes, increase the use of Advance Care Plans (see below), and supportive care registers.

Integrated working was also developed in Early Intervention pilot projects including Older People's Assessment and Liaison (OPAL), the establishment of Early Intervention Community Teams, and the creation of hospital discharge hubs. These projects enabled colleagues across the system to develop referral routes and deliver an education programme to help prevent avoidable admissions to hospital, facilitate timely discharge home, and improve symptom management (e.g. effective pain relief).

The key process for integration of care is Advance Care Planning (ACP), a voluntary process of discussion and review designed to help people who have the capacity to indicate their preferences and wishes for future care (DH, 2012). It is widely recommended as a basis for the organisation and delivery of end of life care (Marie Curie, ND; Compassion in Dying, ND; RCGP/RCN [Royal College of General Practitioners/Royal College of Nursing], 2012). ACP involves a series of conversations in which a person's wishes are explored, identified, recorded and retained in accordance with local policies as part of a system which enables health and social care professionals to share information (DH, 2012). ACP improves end of life care, increases patient and family satisfaction, and reduces stress, anxiety and depression in surviving relatives (Detering *et al.*, 2010). Strategies are needed to implement ACP in policy and practice (Ampe *et al.*, 2016), and consistent use of General Practitioner (GP) registers to ensure more people are identified earlier as they approach end of life is a key element of such strategies to help ensure everyone in their last year of life has the opportunity for an advance care conversation.

Level 3-Coordinated Services

Although there were pockets of excellence, patient stories of their experiences and consultation with stakeholders demonstrated the system was fragmented, which made it difficult for patients and families to know who to call in an emergency. A co-ordinated system of care with a single point of contact was established staffed by an Advanced Nurse Practitioner or Clinical Nurse Specialist 24/7 to reduce the burden on Paramedics, GPs, District Nurses, Care homes, Accident and Emergency departments, carers and patients. This service directs the patient to the most appropriate place of care if their needs cannot be met at home (NCPC [National Council for Palliative Care], 2017).

Level 4-Specialist Services

If the Civic, Integration, and Coordination levels of the new model (Figure 3) are effective, demand on the specialist and acute level services will reduce significantly, although referrals may increase as a result of better identification of those in need of specialist services. In which case specialist services will work with the co-production working party to explore how best to provide consistent access to appropriate services at any time, admission to hospice in-patient care for example.

Discussion

Large-system transformation (LST) involves interventions aimed at co-ordinated system-wide change affecting multiple organisations and care providers with the goal of making improvements in the efficiency of health care delivery, the quality of patient care, and population-level patient outcomes (Best *et al.*, 2012).   It has been argued that systems science is making an important contribution to the development of evidence based-policy (Willis *et al.*, 2014), however Atkinson *et al.* (2013) identified 21 frameworks used in large scale transformation projects and concluded there was insufficient evidence to determine which factors were more or less important than others in system change. The development and implementation of the model reported here are now considered in the context of these principles.

Distilled from a realist review and evidence synthesis of 84 empirical studies of LST in a range of contexts 5 'simple rules' for LST are offered to guide the process (Best *et al.*, 2012; Best *et al.* 2010) (see page 3). In simple terms the LST of PEoLC followed these rules. The PEoLC co-production Working Party (see figure 1) consulted with a wide range of stakeholders and STP partners to produce the new, integrated model. There was clear leadership of the overall co-production effort from a designated hospice chief executive and palliative care consultant, and distributed leadership was undertaken by the members of the co-production working party to develop elements of the model. There was frequent and open communication among all stakeholders, at the main meetings and between the meetings. This was founded on understanding of the context, as the network of people involved had extensive knowledge and experience of the setting and the history of the organisation and delivery of PEoLC in the area. However attendance was not always consistent because of work pressures and this resulted in the same issues being discussed several times to ensure all stakeholders were up to date and informed. Although this was an inclusive approach, it was time consuming and it is likely faster progress would have been made with regular involvement of all group members.

There was engagement of clinicians, and patients and their families contributed through the range of representative groups involved in the co-production working party. Yet this 'simple rules' approach has been criticised for being normative, adopting the concerns of senior managers, and that the elements 'engage physicians' and 'involve patients and families' are co-optive devices which neglect issues of politics and power (Jones *et al.*, 2019). This is deemed to be problematic because it frames the debate, determines how the problem is

understood, and who is included in decision making (Jones *et al.*, 2019). For example it is important not to make assumptions about the nature of community based organisations which although important social care system stakeholders, are extremely diverse in terms of scope, scale and engagement (Wilson *et al.* 2012). In addition Turner *et al.* (2016) found the Best (2012) framework useful for identifying key processes in the transformation of stroke services, but it produced an incomplete account of change and that attention to history did little to facilitate system transformation.

This reveals the tension between identifying practical steps and actions those wanting to bring about change to improve services find helpful and applicable, and the need to be mindful of whose values and priorities they reflect. We endeavoured to achieve this balance, however the group membership was made up of health professionals, charities and representatives of other statutory organisations in the main and so we cannot guarantee misplaced assumptions were not made concerning the community-based organisations involved. In future system change efforts, greater involvement of patients and families would help to offset any such imbalances if managed appropriately. It also suggests that other elements of systems theory need to be taken into account when approaching LST. For example Greenhalgh *et al.*, (2012) recommend incorporating a systems approach from the outset, which informed the development of the model reported here. Also the recognition that the knowledge needed for LST spans multiple organisations, is held by individuals, embedded in relationships and is value laden (Greenhalgh *et al.*, 2012), was reflected in the breadth of membership of the co-production working party and the constructive/collaborative work undertaken. Although as noted above-more consideration of the role and contribution of patients and families would improve system design by ensuring a wider range of voices was heard and acted on.

However if the more detailed evidence and guidance concerning LST is considered the scale of the challenge facing leaders in health and social care and the public becomes clear Atkinson *et al.* (2013) identified thirteen factors that influence large-scale change in health care and Nancarrow *et al.* (2013) synthesised eighteen propositions of key factors for success in large scale workforce change, tested them empirically against 55 projects of workforce redesign, and derived three broad principles: 1. Drivers for change need to be closely linked to clinical practice and patient care. 2. The context for workforce change must be supportive at all levels. 3. Mechanisms for workforce change should include engagement of key stakeholders, access to resources for implementation, a change management process, and

governance and support structures. Systems thinking perspectives can help address the challenges of LST, because they focus on promoting the value of relationships; recognising the nuances created by context; the need to understand system behaviour over time; and that knowledge production and core functions are vital for transformative efforts (Willis *et al.* 2014). However, the potential for systems to benefit from this approach is limited by the complexity of the processes required and the sheer number of issues to be addressed in practical terms by policy makers and change leaders.

The challenge of implementing change in health and social care systems can seem overwhelming, many of the challenges are a consequence of human actions and so human action can be mobilised to overcome them (Holmes *et al.*, 2017). However leading across complex interdependent systems of care is a new and different role (Fillingham and Weir, 2014). Delivering integration in service provision requires investment in discovery and leadership learning across systems, because integrated services must be developed and led in the context of local needs- there is no one-size-fits-all model (Fillingham and Weir, 2014). Two of these requirements have been met: Leadership learning across the system occurred (in the form of the system leadership programme) and the model was co-designed to address local needs. The co-production approach to the design of the PEoLC model established a firm foundation for sustained LST. Indeed in response to the COVID-19 pandemic many of the high impact changes (Figure 4) were implemented at an accelerated pace including:

- a multi-provider coordination centre (Birmingham and Solihull Clinical Commissioning Group, 2020)
- education by webinar on advance care planning to over 40 general practices
- recruitment and online training of advance nurse practitioners for enhanced care to care homes
- a hospice telephone bereavement service in partnership with the City Council

Which was only possible because the collaborative approach of the co-production working party had already been developed. In order to meet the third requirement for system change, discovery (Fillingham and Weir, 2014), work is need to investigate the impact of these changes to identify the factors that are integral to system change (Atkinson *et al.* 2013).

Conclusion

A co-operative model of practice and service design that fuses clinical and community expertise and civic society has been advocated as necessary to capitalise on the interdependence of these sectors to create compassionate communities and cities which can deliver integrated palliative care services (Abel *et al.*, 2018). The model designed by the co-production working party enabled this to be realised. However the lack of empirical evidence in this area reflects the difficulties involved in evaluating large scale change in complex systems and integrative research methods and new approaches are needed to garner such evidence (Atkinson *et al.*, 2013). There is a need to compare and contrast lessons learned by designing prospective comparative case studies that use common terminology and study similar interventions in varying contexts, which take account of the political context of transformational change (Best *et al.*, 2012). The intervention reported here constitutes such a case study.

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Table 1: Key Definitions

Term	Definition
End of Life Care	End of life care involves treatment, care and support for people who are nearing the end of their life. It's an important part of palliative care. It is for people who are thought to be in the last year of life, but this timeframe can be difficult to predict. Some people might only receive end of life care in their last weeks or days. End of life care aims to help people live as comfortably as possible in the time they have left. It involves managing physical symptoms and getting emotional support for people and their family and friends (Marie Curie, 2018).
Palliative Care	Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (WHO, 2019)
Supportive Care	Care given to improve the quality of life of patients who have a serious or life-threatening disease. The goal of supportive care is to prevent or treat as early as possible the symptoms of a disease, side effects caused by treatment of a disease, and psychological, social, and spiritual problems related to a disease or its treatment. Also called comfort care, palliative care, and symptom management (NIH, ND).

Table 2: Alignment of the six National Ambitions for Palliative & End of Life Care and the 10 high impact changes.

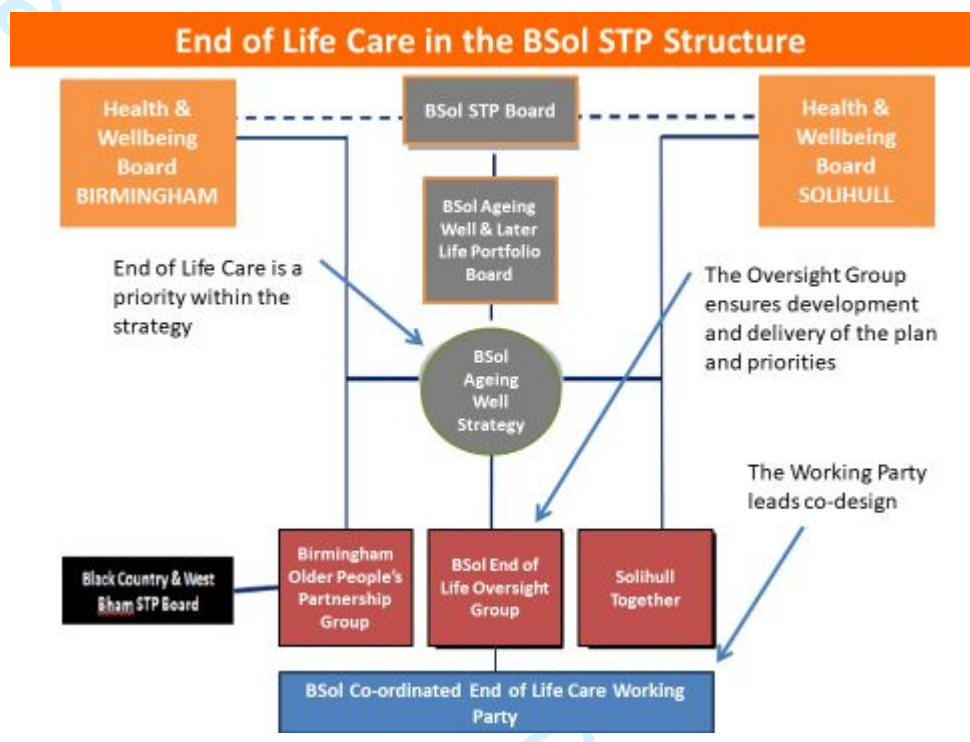| Ambition	High Impact Change
Ambition 1 – Each person is seen as an individual	1, 7, 8
Ambition 2 – Each person gets fair access to care	2, 3,9
Ambition 3 – Maximising comfort and wellbeing	1,4,5,8
Ambition 4 – Care is coordinated	4, 5, 6,7
Ambition 5 – All staff are prepared to care	1, 3, 8, 10
Ambition 6 – Each community is prepared to help	1, 3, 4, 9, 10,

Figure 1: Co-Production Working Party

The membership of the group varied depending on staff availability and the stage of the work. In total there were 73 people involved in this work. Examples of those involved are included below.

Role	Organisation
Medical Consultants in Palliative Care	Hospice (2) Acute Hospital (5)
Chief Executives/Senior Managers	Hospice (4) Ambulance Trust (1) Clinical Commissioning Group (6)
Senior Nurses	Hospice (5) Acute Hospital (3) Clinical Commissioning Group (1) Community Trust (1)
Elderly Care Consultants	Acute Trusts (3)
General Practitioners	5
Community Nurses	7
Service User Groups	3
Voluntary Agencies	3
Specialists	Information/Data Specialist (1) Remote Technology Industry Specialist (1) Arts Therapist

Figure 2: End of Life Care System Structure

End of Life Care in the BSol STP Structure

Health & Wellbeing Board BIRMINGHAM

BSol STP Board

Health & Wellbeing Board SOLIHULL

BSol Ageing Well & Later Life Portfolio Board

End of Life Care is a priority within the strategy

BSol Ageing Well Strategy

The Oversight Group ensures development and delivery of the plan and priorities

The Working Party leads co-design

Black Country & West Bham STP Board

Birmingham Older People's Partnership Group

BSol End of Life Oversight Group

Solihull Together

BSol Co-ordinated End of Life Care Working Party

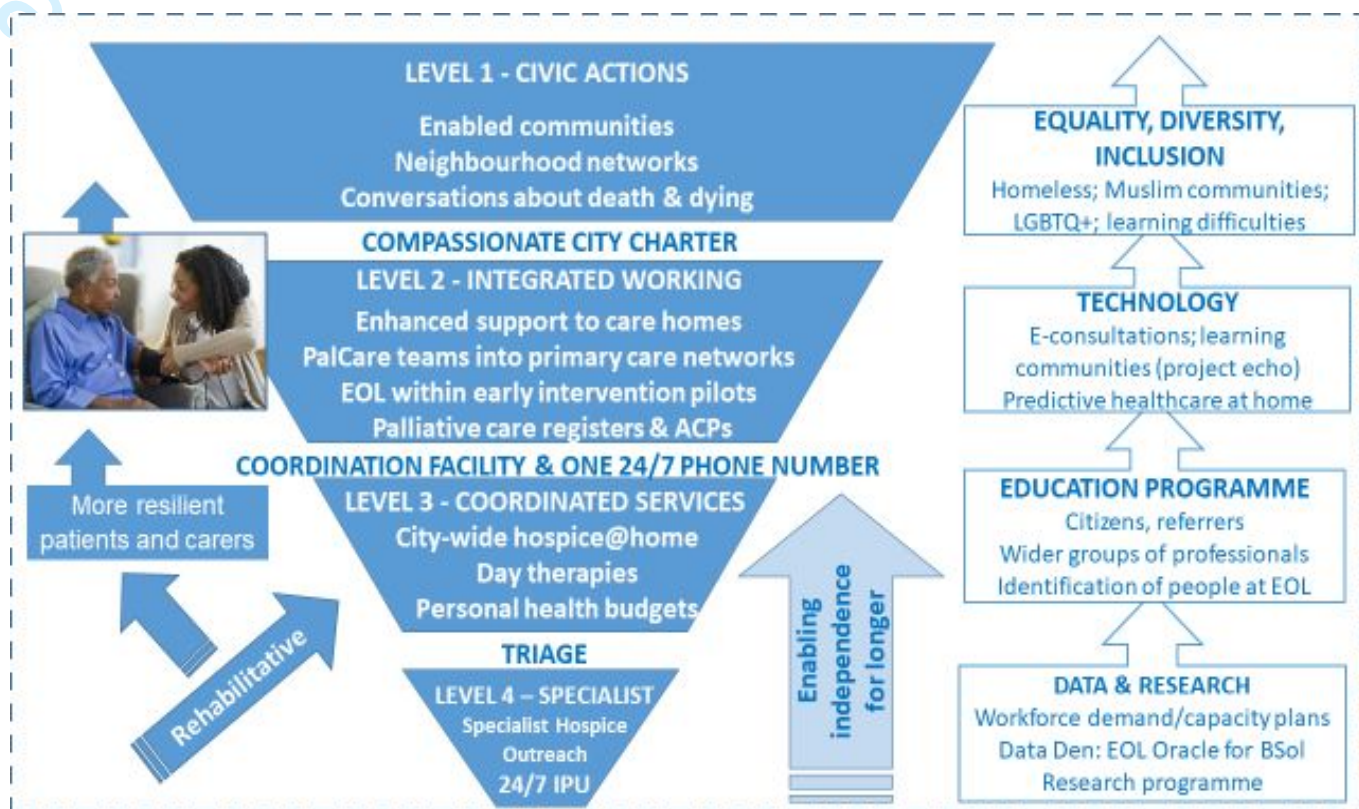Figure 3: A model for excellence in palliative and end of life care

Figure 4: Ten High Impact Changes to Deliver Service Transformation

1. **Conversations for personalised support and care**-we will work with people to make it normal to talk about death dying and loss. We will support the societal change required to do this.

2. **Recognising when someone is at the end of life-** we will recognise people who may be in their last 1000 days and those closer to dying so we can make sure they have the right care it is needed.

3. **Learning and Education-** we will teach professionals, individuals, and communities about end of life care so that they are better able to share that care. We will also learn from communities.

4. **Funding to improve access**- we will do everything we can to get the money needed to improve care at the end of life.

5. **Equality, diversity and inclusion-** we will work with others to ensure equitable care at the end of life for everyone whoever they are and whatever their circumstances.

6. **Coordination of Personalised end of life care-** we will make sure services are available twenty four hours a day and are easy to access. We will test out new ways of coordinating services to make it easier for people to get help. We will make use of personal health budgets, continuing health care funding, and social prescribing to ensure individual choices are better met.

7. **Digital and estates innovation to support a responsive model of care-**we will organise our computer systems so that connect with each other and keep personal information safe. We will use this technology and our buildings to make it easier for people to get support when and how they need it.

8. **Leadership**-senior leaders will work together to ensure that the whole system works as effectively as possible.

9. **Compassionate City Charter and community led end of life care-** our Compassionate City Charter will ensure that everyone starts to listen to what matters to people at the end of life. We will work with communities who are already delivering end of life care and help to equip more citizens to play a part in end of life care.

10. **Centre of excellence for palliative and end of life care-** We want Birmingham and Solihull to be recognised as a UK leading centre of excellence for palliative and end of life care. We will work together to achieve excellence in education, research, social and clinical practice for the best possible experience at the end of life where our last 1,000 days of life have as much importance as our first.

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Response to Reviewers' comments

Reviewer 1 Comment	Response
Thank you for the much improved manuscript. This is of interest to an international audience and has potential to inspire others in change processes. If possible, I would like to read a more elaborated text with strengths and weaknesses of the approach, the process and the outcomes. It seems to be mostly about strengths. Best wishes going forward!	Thank you for your insightful and supportive comments and your good wishes. Some further critical content has been included in the discussion to reflect the challenges and difficulties encountered during the transformation work. These changes are indicated in red font.
I would wish for a more critical approach to the process, at present it seems mostly to be about strengths. Including weaknesses or lessons learned along the way would benefit readers.	Additional content concerning challenges and lessons learned has been included (indicated in red font).
Towards the end (page 11, line 43) there is a long sentence that could be divided.	Thank you. This sentence has been separated into two sentences.
I feel that the end (before the conclusion) is somewhat abrupt and does not measure up to the quality in the rest of the paper.	Additional content has been added to provide a better link between this section and the conclusion.
Reviewer 2 Comment	**Response**
Accept	Thank you for your helpful and supportive comments, much appreciated.