# Creating an Evidence Centre for Palliative and End of Life Care

## Report from stakeholder workshop

**21 March 2022, Marie Curie, Albert Embankment**

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## Introduction

The Social Care Institute for Excellence (SCIE) was commissioned by Marie Curie to carry out a short study into the feasibility of a new evidence centre for palliative and end of life care (PEOLC), which would cover all age groups. SCIE conducted a rapid review of relevant literature and interviews with stakeholders involved in palliative and end of life care research and evidence dissemination to explore the case for a new centre, its potential purpose and role (the SCIE report is appended in Appendix 1).

In parallel, Professor Katherine Sleeman, Laing Galazka Chair in palliative care at the Cicely Saunders Institute, King's College London has been developing a proposal for a What Works Centre for palliative care, supported by Dr Anna Dixon, Prof. Baroness Ilora Finlay and others. The development work involved conversations with key stakeholders across Government, including the Cabinet Office What Works team.

Leading on from these activities SCIE, supported by Marie Curie and with input from Katherine Sleeman, facilitated a workshop with a wider group of stakeholders to discuss the proposed concept of a PEOLC evidence centre and emerging options for its development, including the purpose of such a centre, its potential position and impact within the wider sector, and possible form and funding models.

The workshop was held at the Marie Curie head office in London on 21 March 2022 and involved a range of representatives from across the spectrum of PEOLC evidence users, generators and facilitators, as well as from existing What Works centres and potential supporters, to help shape and develop the concept at this formative stage (the attendee list can be found in Appendix 2).

The session involved short presentations from SCIE and Professor Sleeman (these are contained in Appendix 3) and facilitated group discussions. The purpose of the workshop was to:

- elicit stakeholder feedback on the idea of creating an evidence centre for PEOLC and emerging options for its development, including:
    - the case for the centre's establishment
    - potential position and impact within the wider sector
    - adapting best practices from similar centres
    - potential organisational form, funding and governance model
- discuss next steps for developing the proposal and testing it further
- generate wider support for the proposal among sector leaders, stakeholders and potential funders.

The agenda for the session is shown below.

**Workshop Agenda, 21 March 2022**

| Time | Discussion | Notes |
|---|---|---|
| 13.00 | Lunch on arrival | |
| 13.30 | Welcome and introductions | Dr Sam Royston, Marie Curie |
| 13.35 | Transforming care for people approaching the end of life: the case for an Evidence Centre | Professor Katherine Sleeman, KCL |
| 13.50 | Proposal for an Evidence Centre – Background and initial concept | Ewan King and Deborah Rozansky, SCIE |
| 14.05 | Whole group Q&A | All |
| 14.15 | Group discussion: What is the case for an evidence centre? | Ewan King and Deborah Rozansky |
| 14.50 | Comfort break | |
| 15.00 | Group discussion: Developing the proposal further | Ewan King and Deborah Rozansky |
| 15.40 | Whole group plenary | All |
| 15.55 | Thanks, concluding remarks and next steps | Sam Royston |
| 16.00 | Workshop closes | |

## Session One: What is the case for an Evidence Centre?

Following on from the presentation, participants were engaged in two participative discussions, facilitated by SCIE.

The first session involved participants being asked to consider the case for a new evidence centre – answering the question: Do we need a new Centre for Evidence in palliative and end of life care?

***"The case for change has rarely been stronger – especially as we come out of the worst of the pandemic. The inequalities are rising."***

All the participants at the workshop felt that there was a strong case for a new Evidence Centre. Most participants felt that there were significant gaps in the evidence base, evidence synthesis and evidence translation. Participants identified the need for more knowledge and support to apply the evidence in:

- primary care and general practice
- social care
- integrated models of care
- commissioning
- cost benefit analysis

The Centre would have a role to play in convening a coalition of experts and academics with the aim of prioritising areas where further evidence is needed, or where evidence needs to used more effectively to inform decision making and practice.

While the Centre would have a role to play in pulling available evidence together, and maximising the use of this evidence, it was not seen, at least in its early stages of development, as a priority for the new Centre to produce new evidence. The primary focus of the Centre instead would be to translate this evidence into relevant and actionable guidance and advice on how services could be improved, and to help decision-makers act on that guidance/advice.

Other points raised included:

- The Centre should focus on how to make things better – especially the critical piece of translating evidence into practice, e.g. from highlighting service gaps to improving services.

***"The Centre's remit should be about helping practitioners to improve care, by making evidence accessible and available in spaces where they already are."***

- The Centre needs to be truly co-created with key stakeholder groups, including people with lived experience, evidence users and policy makers. In particular, the needs of people with lived experience should be at heart of the evidence centre, helping to shape its priorities.

***“There is huge power amongst the partners – and those who lead care – this is why we need to harness everyone’s voice as part of this.”***

- Most participants wanted to see the Centre adopt a broad definition of end of life care, to include community-based and social care approaches to end of life care and avoid simply focusing on specialist palliative care.

***“We must avoid adopting a narrow view of what we mean by end of life – I would prefer we adopted a broad-scope, rather than narrow view of palliative and end of life care.”***

In formulating its evidence strategy, the Centre might draw on three types of evidence, mirroring the model adopted by the Centre for Aging Better: evidence from the experience of practitioners, formal evidence from research and evaluations, and evidence from people with lived experience of drawing on health and care services.

Other functions of the Centre could include:

- acting as a focal point for identifying research priorities for the sector, acknowledging research priorities already developed elsewhere in the sector and the need to not overlook innovations or less researched areas of practice.
- creating and overseeing a set of standards of evidence for end of life care research
- providing guidance to research producers on producing high quality research
- building a clear map of existing evidence
- developing tools which support the use of evidence in day-to-day practice, such as decision aids, cost benefit analysis for commissioners and quick guides.

***“We need to avoid simply focusing on clinical research – which whilst important, doesn’t tell you enough about how to implement improvement.”***

## How might an evidence centre best operate?

In the second session, participants were asked to consider in more depth the purpose, funding, governance options and approach to setting up the Centre.

Key points arising from the discussion included:

### Aims and areas of focus

Most participants felt the primary focus of the Centre should be on outcomes – how do we improve outcomes and reduce inequalities for people drawing on palliative and end of life care? As one person put it: it should be ‘beneficiary led rather than government or sector led.’

The purpose and mission should be defined very clearly at the outset. Participants felt the Centre should ideally be UK-wide but recognised that there would need to be national arrangements in place to ensure that its work was not overly dominated by the context in England.

The primary function of the Centre, at least in the initial phase of set-up, would be to promote the translation of evidence into policy and guidance, rather than on the production of new evidence. Over time the Centre may be able to become more involved in commissioning research, especially to fill perceived gaps in the evidence base.

The Centre could also be a location to pioneer innovative approaches to evidence generation, review and dissemination, e.g. novel approaches to systematic reviews and testing of behavioural change models of sharing evidence.

The Centre’s focus should also be broad, focusing not just on generalist palliative care, but also service commissioning, integrated care, innovation, social care and children and young people’s end of life care.

***“Very little evidence to support generalist palliative care is available, need to look at the whole piece, not just specialist palliative care – the scope of the Centre should be broad, all-age, cross-boundary, adopting an expansive definition, and include social care, not just a medical model.”***

### Audiences

There was a strong view among participants that commissioners (commissioners are professionals who are responsible for organising how health and care services are planned, purchased and monitored) were a key audience for this new centre. Currently, it was felt that commissioners lack high-quality evidence to support funding and commissioning decisions, and that the new Centre needed to provide better evidence to support this group in the future.

Other audiences that were seen as important to the Centre were:

- regional clinical networks
- policy makers – including those closest to funding decisions

- senior health and care practitioners – who are involved in designing and delivering new services
- people with lived experience

***"A key audience is commissioners – we need to involve them from the start, helping them understand how we turn what we know from evidence into commissioning contracts."***

## Engagement with the sector and wider audiences

Participants were of the view that there was a need for true co-production of the Centre's aims and priorities.

The new Centre will need the skills and capacity for good co-production and engagement, in the same way that the new IMPACT Centre for adult social care has a team of dedicated co-production experts. The Centre should explore varied methods, including ethnography, to understand the perspectives and lived experience of patients and family carers.

The greatest potential of this Centre will come from harnessing and magnifying existing expertise, rather than trying to do everything from scratch. The Centre needs to become adept at building collaborations with other academics and sector leaders, rather than going it alone.

## Funding

There wasn't a single view of how funding should be obtained for the new Centre. It was agreed that the funding for this Centre should be in addition to existing research funding, and not replace any current funding to research centres.

There was strong support for the Centre receiving an endowment or at least a long-term funding settlement to give it the time and space to develop as an organisation and demonstrate its worth; however it was agreed that this may not be possible.

Another alternative was to explore building a coalition of funders who could all contribute with resourcing, including government, charitable and research funders, such as NIHR and ESRC. Such a mixed funding model would mean the organisation would be more likely to develop resources that are relevant to a broader range of stakeholders, rather than being driven by the interests of a single funder.

## A phased approach to establishment – incubation or start-up?

Most participants were of the view that it would be good to start small and use the initial 'start-up' phase of the Centre's life to explore in more depth the purpose and priorities, organisational form of the Centre, mirroring how the IMPACT and Children's Social Care evidence centres were established.

There was some support for the Centre being an independent charity, but not initially. One potential model would be to establish the Centre along the lines of a start-up – a small, agile development centre which works out in more detail its purpose over the first few years of its existence. Another model is a start-up or 'incubator' mode, whereby the centre is supported by a larger pre-existing organisation through the first few years of its life.

This phased approach to establishing the centre, it was argued, would reduce the risks of the Centre investing too early in the wrong model and not building the wider sector support to be successful and have impact. A phased approach also supports building a viable business case for long-term investment of resources.

## Staffing

Some participants suggested that the staffing for the Centre should initially focus on providing credible, well networked leadership for the Centre, rather than building a large research team. This small team would enable the Centre to quickly raise its profile and establish its credentials. To find the right people in a short time frame, secondments were suggested as a possible option.

Participants also highlighted the importance of building a team with a broad range of skills. In addition to researchers and academics, the key skills and capabilities needed include:

- leadership and change management
- strategic skills
- co-production and stakeholder engagement
- programme and project management
- communication, branding and marketing skills
- evidence synthesis skills.

## Governance

The workshop participants did not have strong views on the exact governance model the Centre should adopt, emphasising instead that the governance structures would evolve once the purpose of the Centre is defined.

To this end, it was felt that a start-up or ‘incubator’ phase in the development of the Centre could be used as an opportunity to test out potential governance models rather than commit too early to a defined model.

There was a strongly held view, however, that the final organisation should reflect a coalition of interests, including people who draw on support and families, so that it “truly represents the views of the sector and people who we support”.

Participants also felt it would be essential to involve people with lived experience in the governance of this nascent organisation.

## Six ‘I’s

During the second participative session at the workshop, six principles were identified for how the Centre might work in the future. While further discussion with stakeholders is required to explore the detail of how a new centre might work, these initial principles were seen as a good starting point for future discussions.

These were named the six ‘I’s.

1. **Independence** – Operational independence was seen as a vital precondition for the success of the Centre. The Centre’s ‘north star’ which drives its activities should be the improvement of outcomes and reduction in inequalities around end of life care.

***“Whilst we may need some government money, we cannot be seen as being dictated by government political imperatives. We should be seen as an independent and authentic voice.”***

2. **Immediacy** – the time for coordinated action on evidence is now, and we should build on this moment to establish the Centre without delay.
3. **Incubation** – the Centre should start small, being incubated by a larger organisation as it engages the sector and determines its purpose, funding and structure.
4. **Inequalities** – the Centre’s overriding purpose will be to produce and share evidence which serves to reduce the huge inequalities which exist in quality, access and outcomes in PEOLC.
5. **Interdisciplinary** – the Centre will require a multidisciplinary team to make the difference it needs to make – involving academics, policy experts, marketing and communication experts, people with knowledge of behaviour change and co-production.
6. **Impact** – the Centre will only be successful if it can have a tangible impact, by translating evidence into changes to services and improving outcomes.

## Next steps

The workshop was a useful starting point for testing the concept of the PEOLC Evidence Centre and the potential for wider support. Additional feedback from workshop participants is being sought in response to this record of the event.

A much broader discussion is also needed to develop and refine the proposal further. These engagement activities are likely to include:

- interviews with stakeholders who were invited to the workshop but couldn’t attend
- further workshops with evidence users, including local and national policy makers and people with lived experience and family carers, to understand their priorities and needs
- engagement with potential initial funders for an incubator/start-up centre.

## Appendix 1: SCIE Evidence Centre scoping report

# Creating an Evidence Centre for Palliative and End of Life Care

***Briefing paper**: March 2022*

## Introduction

This short paper presents the summary of findings from a rapid scoping exercise, commissioned by Marie Curie from the Social Care Institute for Excellence (SCIE), to explore the feasibility and potential role and operating model for a new Evidence Centre for Palliative and End of Life Care (PEOLC). This scoping exercise involved a review of relevant policy and evaluative literature about evidence centres and included interviews with six senior stakeholders from across the academic, clinical and policy landscape.

The paper also draws upon SCIE's experience of being part of the Incubator which established the What Works Centre for Children's Social Care, and SCIE's involvement in the delivery of the NICE Collaborating Centre for Social Care and Leadership Team of the new ESRC / Health Foundation Funded IMPACT Centre.

## The challenge

The evidence base for PEOLC is underdeveloped, with significant gaps in the research necessary to support improvements in clinical practice, service model design, patient experiences and care outcomes. Research questions reflecting the needs of people with lived experience and their carers are not routinely prioritised. Evidence from existing research is often not translated into practice or widely disseminated, and innovations in practice are unsupported or not sustained.

Current resources for research, research infrastructure and knowledge translation activities are limited and uncoordinated across the sector. Although there is growing recognition of the critical research gaps, there is no consensus about where to focus the funding or how to expand the resources available.

Compared to many other sectors, there is a strong view that PEOLC research is underfunded.

## Initial thoughts on role of the Evidence Centre

There was agreement among those we interviewed that a new Evidence Centre would add value to the current research landscape for PEOLC, mirroring developments in other sectors, such as adult social care, children's social care, older people's services, health and schooling and policing, which now have What Works Centres or well-funded evidence centres.

The scoping exercise supported establishing a new independent evidence centre to support innovation and improvement in PEOLC. The purpose of this Centre might be to:

- develop a shared framework and priorities for tackling critical research questions and evidence gaps
- leverage this framework and shared priorities to develop new sources of research funding
- facilitate the generation of new evidence through funding research collaboratives and initiatives with partners and stakeholders
- lead the synthesis and translation of evidence to support innovation and improvement: new models of care, clinical practice improvement, care delivery and care experiences
- support the adoption and dissemination of evidence to accelerate improvements in the organisation, commissioning and delivery of PEOLC.

The beneficiaries of the evidence centre would be wide-ranging, including: an interdisciplinary research community; research funders; sector partners such as service commissioners and providers; clinical leaders; people at end of life, their carers and front-line professionals.

## Initial thoughts on the Evidence Centre's focus

The initial scoping interviews found enthusiastic support for creating an Evidence Centre focused on building the evidence base in PEOLC and addressing critical research gaps. Interviewees were asked about what they thought an Evidence Centre might do and what it might achieve, as well as their views about how the Centre might develop initially.

- Clear links between gaps in research and the need to make improvements in clinical practice, service models and care experiences and outcomes were drawn:

  > *"The opportunities are many, but the resources are few."*
  >
  > *"The current system emerged out of good ideas, rather than evidence."*
  >
  > *"The absence of economic evidence is holding us back."*
  >
  > *"The care models are not fit for purpose."*
  >
  > *"We don't have a good sense of what good looks like for different communities."*
  >
  > *"Inequalities in access are real."*

- The interviewees suggested the Evidence Centre be positioned to support applied research as a network leader. There was agreement that we need to generate, gather, translate and disseminate better evidence on clinical and care model improvement in PEOLC.

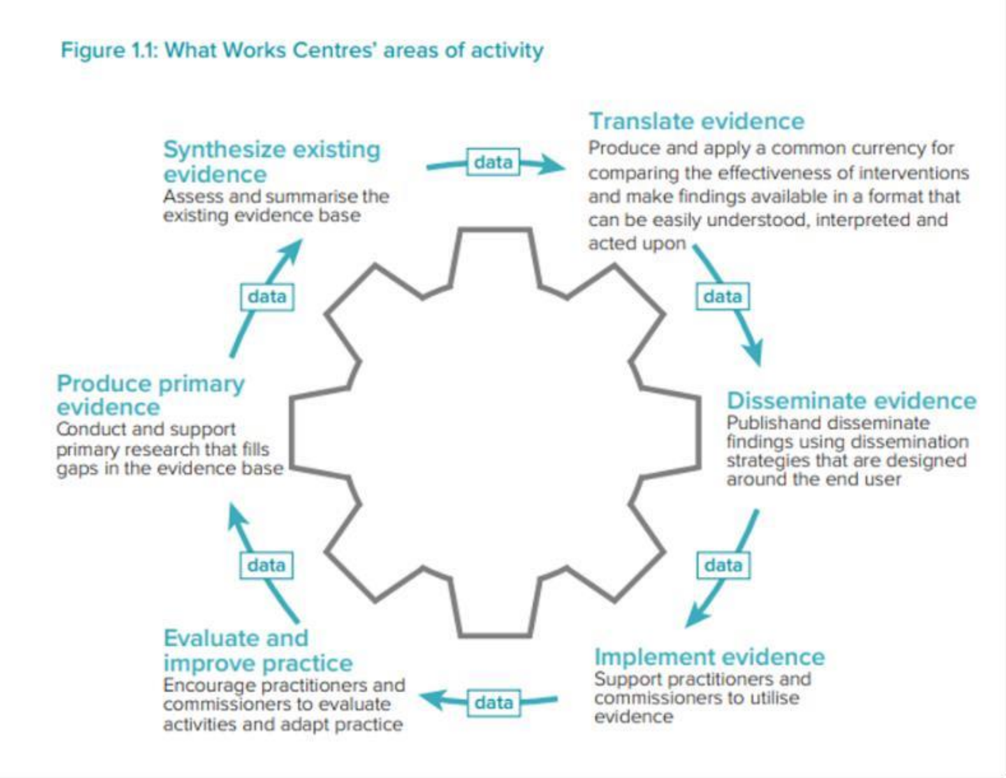
- They suggested a shared endeavour with the sector, with the Evidence Centre positioned to convene partners and engage with stakeholders to ensure its strategy and activities complement the work of other researchers and institutions.
- There was a general view that while the gold standard of research – represented by Randomised Control Trials – is desirable in many cases, this Centre needs to be able to generate and draw on a broad range of evidence, including practitioner wisdom, the views of people with lived experience, and qualitative research. Mixed views were received about the Centre having a role in clinical efficacy studies; further exploration of this might be needed.
- Different forms of evidence would be relevant for the Centre’s work, and research methodologies from different disciplines and fields would be employed. This approach would recognise the multi-professional characteristics of the PEOLC sector, its workforce and the nature of PEOLC services themselves.
- There was also a view that about a lack of evidence on effective commissioning and how to develop and scale innovative models of care. The Centre could play a role in testing, evaluating and informing the roll out of new models of PEOLC.
- Those interviewed felt strongly that the contributions of people with lived experience and their carers should be instrumental in shaping the Centre’s work programme, focusing on important gaps in research evidence and practice.
- The Centre would also share evidence with governments and the NHS to inform policies that further the adoption and diffusion of research insights and innovation.

Those we interviewed felt that the development of this Centre, when it happens, would need to be gradual and carefully considered, ensuring that the very broad range of stakeholders in this sector are fully involved in its creation. In its initial 12–18 months, the Evidence Centre could work with partners to establish the Centre’s leadership, strategic aims and operating model; engage with the wider sector to set an initial research agenda and funding strategy; and describe its methods and approach to evidence generation, synthesis and dissemination.

## Views about the delivery model: applying learning from What Works Centres

Most of those we interviewed considered the national What Works Centre model a favourable template for a new PEOLC Evidence Centre. WWCs have three main functions: knowledge generation, evidence synthesis and translation, and knowledge dissemination to support adoption and spread. Figure 1.1 below illustrates the way WWCs use different types of evidence for their activities, although not every WWC covers all areas. An evaluation of existing WWCs by the Cabinet Office noted that the WWC model has been more effective in improving practice than public policy, although it is expected to inform both.

**Figure 1.1. Activities of What Works Centres**



Source: What Works Centre Network, ‘The What Works Network: Five Years On’, 2018.

Currently, there are nine independent WWCs (as well as three affiliate members and one associate member of the What Works Network) organised around distinct policy areas, ranging from ageing and wellbeing to education and children’s services. These WWCs have several common components:

- they act as a platform for connecting researchers with professional practice needs
- they are independent and able to convene a broad set of partners, stakeholders and communities to coordinate interests in common and resources
- they create a space for collaboration and challenging conversations
- their programmes support capacity building for evidence-based research and practice
- they support innovation and support its wider adoption and diffusion, with both policymakers and practitioners
- they complement existing research centres and research agendas.

## Options for leadership and governance

In developing this paper, SCIE looked at a range of possible governance and leadership models for the Centre, drawing on the development of other evidence Centres in recent years. The stakeholders we interviewed were also asked to give us their opinions about these options.

### Overarching principles on governance options

In selecting the right governance structure for a new Evidence Centre, evaluation studies suggest the following principles are important:

- **Independence from funders:** It is essential that funders are not able to influence research findings, which must be derived from the evidence. However, it may be appropriate for funders to feed into decision-making about research questions.
- **Political independence:** Some evidence centres emphasised the importance of being politically non- partisan, while using evidence to shape policy.
- **Accepting that governance might change over time**: Consider what governance arrangements will be needed during different periods of the centre's development, to enable timely and robust decision-making.
- **User and sector involvement:** Involve the centre's users of the research from the outset to inform organisational design and governance.
- **Involving a broad range of experts:** Mix of expertise, including research and behaviour change: ensuring that a governance board includes relevant research methods expertise, policy expertise, sector expertise and representation from people with lived experience.
- **Avoiding organisational capture by a particular sector:** Evidence centres need to be in a position to speak truth to power, whether this is to government ministers, officials or service leaders and end users also need to take precedence over academic interests and priorities.
- **Freedom to publish:** Evidence centres often have an agreement with funders and research partners that the results of their research will always be published. This decision cannot be changed if findings are unfavourable or difficult.

### Governance models:

#### *1. Hosted at a University*

This is where an evidence centre is hosted within a university or partnership of universities, receiving legal, financial and business services support. Under this model, the majority of a centre's staff are employed by the university, but the centre retains a separate advisory or steering group and independent leadership. Formal affiliation with a university host enables the centre to evolve from seed funding and potentially spin out as a separate entity after a period of time.

**Pros**

- access academic funding, e.g., NIHR and ESRC funding
- evidence centres hosted within universities often felt that they benefited from their host's reputation.
- being hosted in a university can bring benefits from business services provided by their host organisations during incubation, such as finance and legal services.

**Cons**

- operating within a strict university governance structure can reduce the flexibility of the Centre to recruit staff and deploy resources.
- danger of host institution becoming overly dominant over direction and decisions in the Centre
- collaboration with researchers and research centres from other universities and organisations requires considerable, ongoing attention, with formal agreements
- challenge involved in trying to establish a new entity within a larger organisation.

**Example: The What Works Centre for Local Economic Growth**

This evidence centre is jointly run by the LSE and Centre for Cities and funded by the ESRC, the Department for Business Energy and Industrial Strategy, the Department for Levelling UP, Housing and Communities, and the Department for Transport. Private industry is also involved. The Centre is led by Professor Henry Overman at the LSE, where he is based. The LSE team also includes economists, who lead and manage the evaluation and support work with local partners.

## 2. Independent charity

This is the most common model for WWCs and other evidence centres, including the Social Care Institute for Excellence, which works on guidance and research delivered within a charity structure. Other charities include the WWC for Homelessness Impact, WWC for Children's Social Care, the Centre for Better Ageing and the Early Intervention Foundation.

**Pros**

- operational independence from government, sector stakeholders and academics
- independence creates scope for building sector consensus about research priorities, establishing research partnerships and leveraging resources.

**Cons**

- during the start-up phase, a new charity might lack infrastructure, finance and business support
- initial leadership of the independent centre will need to be skilled in consensus building as well as organisational development.

- some research funding may not be available to non-academic institutions

**Example: Centre for Ageing Better**

Centre set to explore evidence base for supporting better older lives. Set up as a What Works Centre in response to Government Report ‘Ready for Ageing’ and supported by the Big Lottery Fund to form an independent charitable foundation. The Centre is English based and has been set up as a charity. The non-executive supervisory Board of Trustees has overall legal responsibility for the direction, management and control of the organisation. Ageing Better has four committees: Governance; Remuneration; Finance, Investment & Audit, and Programme & Partnerships.

## 3. Co-produced and sector-led

This model could be a separate entity, supported by different organisations, but co-located within one of the key partners, such as an academic unit or large charity. The centre’s governance and decision-making would be oriented towards the sector, end users and people with lived experience. This shifts the way research priorities are determined and research outputs are produced.

**Pros**

- potential to increase likelihood that research is highly relevant to practitioners and people who draw on support
- due to stakeholders being involved in shaping research priorities they become more likely to use the research once it is produced.

**Cons**

- can lead to conflict between funders and sector stakeholders over the priorities for research
- co-production and engagement is resource intensive and can require expertise which is not commonly held within the research community
- potentially complex structure for leadership and decision-making.

**Example: IMPACT Centre**

The Health Foundation and the ESRC are co-funding a £15m UK centre to lead the way for better implementation of high-quality evidence on innovation and improvement in adult social care. The IMPACT Centre, which is led by Professor Jon Glasby at the University of Birmingham, aims to transform how social care evidence is turned into practice, including supporting adults and young people moving into adult social care, and how social care interacts with partner agencies and other sectors. Ewan King, from SCIE, is a deputy director of the Centre. Its key aims are to:

- Support more widespread use of evidence in adult social care, leading to better care practices, systems and outcomes for people who use services, their families and communities.
- Build capacity and skills in the adult social care workforce to work with evidence of different kinds to innovate, improve care and deliver better outcomes.
- Facilitate sustainable and productive relationships between the full range of adult social care stakeholders to co-create positive change/innovations and improve outcomes for people using adult social care and their families.
- Improve understanding of the factors which help and hinder the implementation of evidence in practice, and using this to overcome longstanding barriers to positive change

**Governance**

- Programme Management Board (executive decision-making body), made up of the funders.
- Advisory Board – experts who provide advice drawn from across policy, practice and academia.
- Leadership Board (executive decision-making) - made up of a mix of academics, service leaders, practitioners, national partner bodies and people with lived experience.
- ‘IMPACT Assemblies’ (two in England and one each in Scotland, Wales and Northern Ireland). These will bring together people with lived experience, carers, practitioners, managers, policy makers, commissioners, providers and researchers in a series of interactive sessions to: identify and build consensus around IMPACT’s priorities; test and refine proposed delivery models; and support subsequent scaling up and cultural change. After IMPACT’s initial co-design phase, these will become ongoing advisory boards for the new centre.

## Options for the business model

### 1. Endowment

An endowment is an aggregation of assets which is dedicated to funding a research centre or university to support its development mission. The endowment’s assets are separately invested, often in perpetuity. Several well-established centres have such funding, such as the Education Endowment Foundation and the Centre for Ageing Better.

**Pros**

- gives the centre greater financial flexibility, as well as the ability to make longer-term plans
- allows the organisation to invest some of the money to grow income over time.

**Cons**

- can lead to complacency and drift as money is guaranteed
- requires intelligent stewardship of endowment resources
- when protecting the endowment, criticism from the research community could emerge because available funding is limited
- potential for added bureaucracy when dispersing funds to researchers.

**Example: Education Endowment Foundation**

Established in 2011 by the Sutton Trust, as lead charity in partnership with Impetus Trust (now part of Impetus–Private Equity Foundation), with a founding endowment of £125m from the Department for Education (DfE). The EEF and Sutton Trust are, together, the government-designated What Works Centre for Education. The EEF only funds projects that will work for the benefit of pupils and settings in England, although supports innovative ideas from overseas that are applicable to the English education system. The EEF’s evidence system and resources (e.g. Teaching and Learning Toolkit) are being applied internationally e.g. in Australia, Latin and South America, and Scotland.

### 2. Government-funded

These are evidence centres who receive primary funding through Government contracts or grants. Examples of this form of Evidence Centre is the WWC for Children’s Social Care, although it is now seeking an endowment. Many WWCs began with seed funding from Government.

**Pros**

- allows the organisation to maintain a tight link to Government and ensure that its work is relevant to national policy

**Cons**

- risk that Government seeks to overly influence research priorities and findings
- can reduce perception of operational independence

- funding can be short-term and change when Government priorities and administrations change.

**Example: Early Intervention Foundation (EIF)**

Centre is focused on early intervention regarding the risks (such as neglect) and protective factors (such as familial relationships) that can affect children's development and life chances. Following the 2011 reports from the Independent Review of Early Intervention by Graham Allen MP (requested by the Prime Minister in 2010), EIF was commissioned in 2013 by Government with cross-party political support and set up as a dedicated charity: independent from, though predominantly funded by, government. The What Works Centre was purposed with assessing evidence and maintains strong relationships with Whitehall.

EIF is predominantly funded through the above four government departments and although the strategy is for this to continue, the Centre aims to diversify funding from private and commercial sources, such as trusts and foundations or local authorities. There is increasing international interest in the Guidebook and other outputs, and EIF's work with local authorities is expected to increase, e.g. via the Early Years Transformation Academy project currently being scoped. The Centre is considering new academic funding/partnership opportunities, how to use the intellectual capital it has built up, and which skills/assets others might purchase (while still producing work for public good)

## 3. Membership and consulting model

This model involves the Centre being funded primarily for paid for services and fees. The organisation may be a charity or social enterprise. The organisation may use some of its surplus to pay for research, but in most cases the research will be paid for through consulting fees and contracts with Government and other funders.

**Pros**

- exposed to commercial pressures which can help to drive innovation, responsiveness to policy demands and rapid research

**Cons**

- can reduce independence as organisation has to derive funding from organisations which might have specific biases or interests
- funding is unreliable and this can make it hard to plan long term
- membership night have sector interests which conflict with the goals of impartiality.

**Example: Research in Practice**

Research in practice is an evidence centre and research consultancy which is focused on children's and adult social care improvement. The Centre is part of the Dartington Trust. The organisation earns the majority of its funding from a combination of membership fees from local authorities and paid-for services such as evaluations, research and training.

### Options for establishing the Evidence Centre

The approach to developing WWCs or other evidence centres has varied between recently established organisations in recent years.

The main option available is to set up an organisation that is hosted by another. This can be a charity or academic centre. This allows the centre to get up on its feet and put in place the organisational structures it need. During this period, a centre may have a 'shadow' board and interim chief executive until it is more fully established and can 'spin off' to become a separate organisation.

Another option is for the Centre to be established through a time-limited co-design or incubation phase, during which the Centre team carry out much more work on the role, function, business model and governance for the Centre.

The WWC for Children's Social Care was set up during a three-year incubation phase during which decisions about its organisational design, funding and governance were made, prior to it making the transition to independent charity.

The IMPACT Centre by comparison, is to be developed over three phases of 'co-design', 'establishment' and 'delivery' to build a centre that becomes a permanent feature of the adult social care landscape, stretching over 10 years of initial funding.

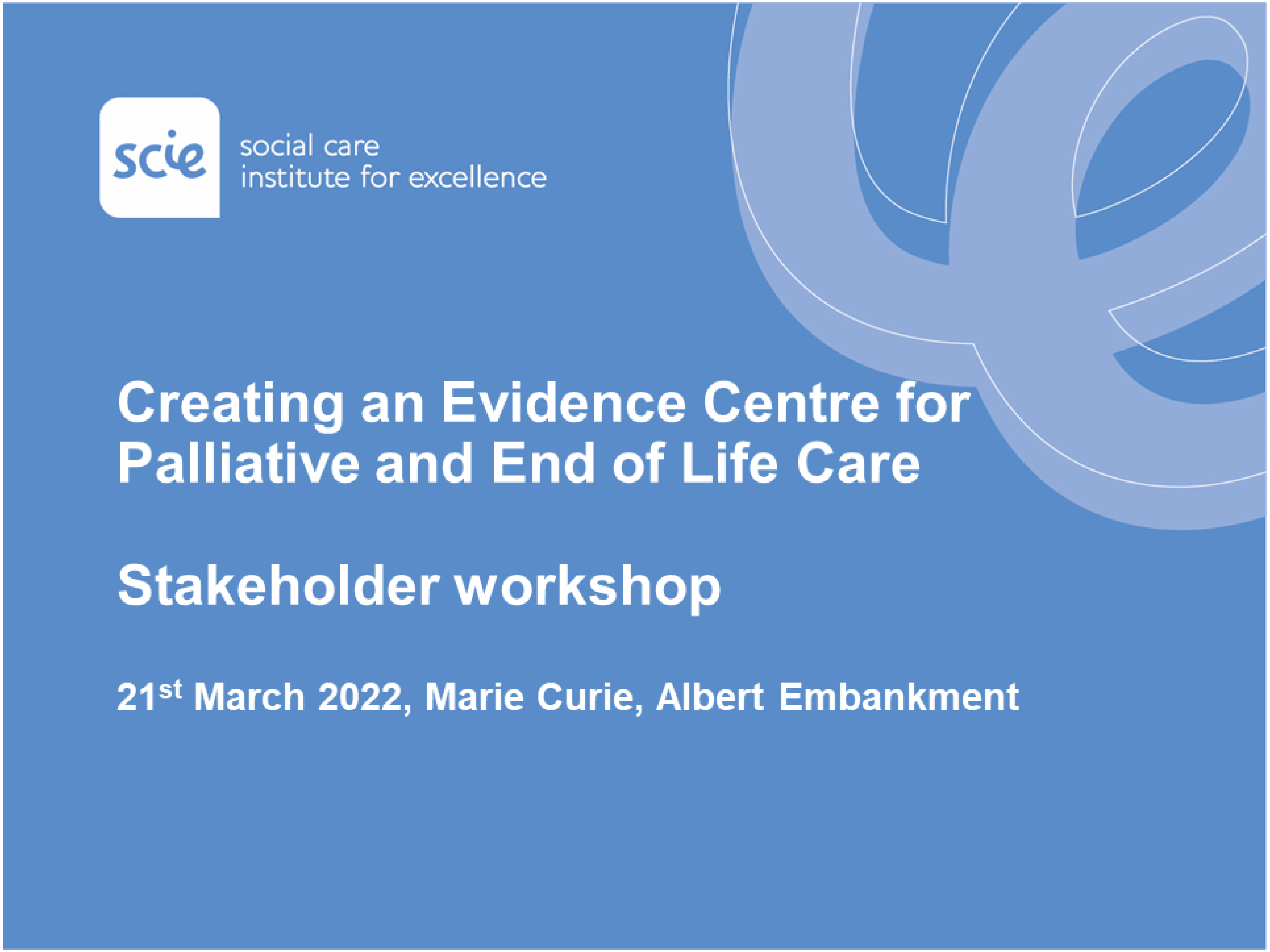
## Questions for stakeholders

1. Do you agree that the PEOLC sector would benefit from an Evidence Centre?
2. What aspects of the proposal do you agree with? What concerns you, and why?
3. Thinking about the areas of activity and common components of What Works Centres, what functions and activities should the Evidence Centre lead and engage in? What should it not do?
4. How might the Evidence Centre engage with partners and other stakeholders, including people with lived experience? What approaches and methods would you recommend?
5. What are some of the pitfalls or drawbacks of establishing an Evidence Centre? How might we address these as the proposal is developed further?
6. How could the Evidence Centre support the research and evidence needs from across whole of the UK?

## Appendix 2: Attendees

| | |
|---|---|
| Anna Bacchoo | What Works for Children's Social Care |
| Dr Cara Bailey | University of Birmingham |
| Dr Sabine Best | Marie Curie |
| Jonathan Breckon | Breckon Consulting Ltd |
| Professor Anthony Byrne | Cardiff University |
| Dr Andy Carson-Stevens | Cardiff University |
| Dr Anna Dixon | Independent consultant; Former Chief Executive of Centre for Ageing Better |
| Dr Helena Dunbar | Together for Short Lives |
| Jonathan Ellis | Hospice UK |
| Ewan King | Social Care Institute for Excellence |
| Dr Sarah Mitchell | University of Sheffield |
| Professor Fliss Murtagh | University of Hull |
| Isabelle Olson | Marie Curie |
| Natalie Owen | Department of Health and Social Care |
| Dr Sam Royston | Marie Curie |
| Deborah Rozansky | Social Care Institute for Excellence |
| Fiona Russell | Local Government Association |
| Dr Libby Sallnow | University College London |
| Giles Skerry | Marie Curie |
| Professor Katherine Sleeman | King's College London |
| Dr Hannah Thomas | Marie Curie |
| Emma Vasey | Sue Ryder |
| Dr Sarah Yardley | University College London |

## Appendix 3: Slides from the workshop



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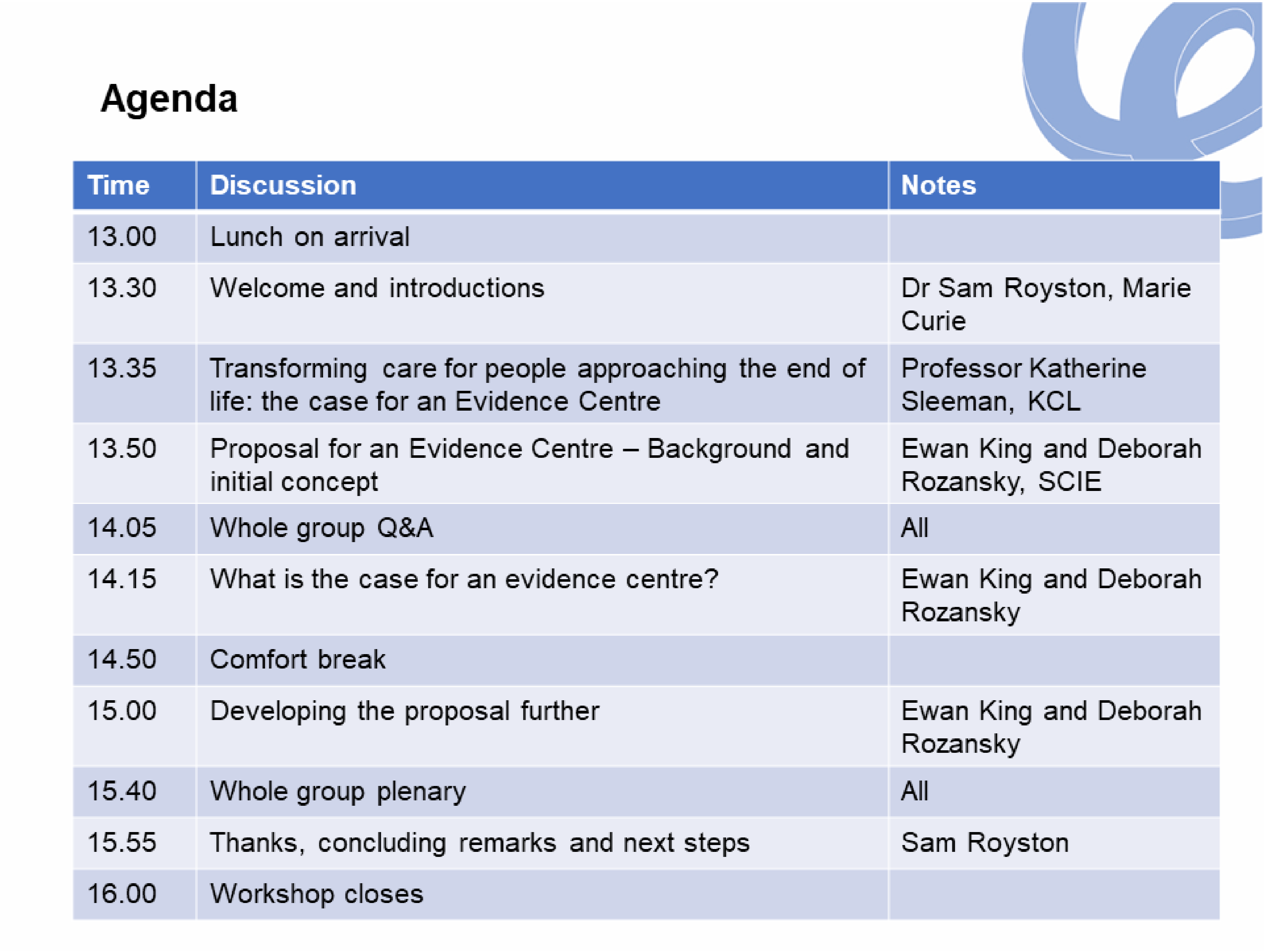
# Creating an Evidence Centre for Palliative and End of Life Care

## Stakeholder workshop

21st March 2022, Marie Curie, Albert Embankment



## Agenda

| Time | Discussion | Notes |
|---|---|---|
| 13.00 | Lunch on arrival | |
| 13.30 | Welcome and introductions | Dr Sam Royston, Marie Curie |
| 13.35 | Transforming care for people approaching the end of life: the case for an Evidence Centre | Professor Katherine Sleeman, KCL |
| 13.50 | Proposal for an Evidence Centre – Background and initial concept | Ewan King and Deborah Rozansky, SCIE |
| 14.05 | Whole group Q&A | All |
| 14.15 | What is the case for an evidence centre? | Ewan King and Deborah Rozansky |
| 14.50 | Comfort break | |
| 15.00 | Developing the proposal further | Ewan King and Deborah Rozansky |
| 15.40 | Whole group plenary | All |
| 15.55 | Thanks, concluding remarks and next steps | Sam Royston |
| 16.00 | Workshop closes | |

Cicely Saunders International
Better care at the end of life

KING'S College LONDON

# Transforming care for people approaching the end of life: the case for an Evidence Centre for palliative and end-of-life care

**Prof Katherine Sleeman**

Laing Galazka Chair in Palliative Care
NIHR Clinician Scientist
King's College London
Cicely Saunders Institute

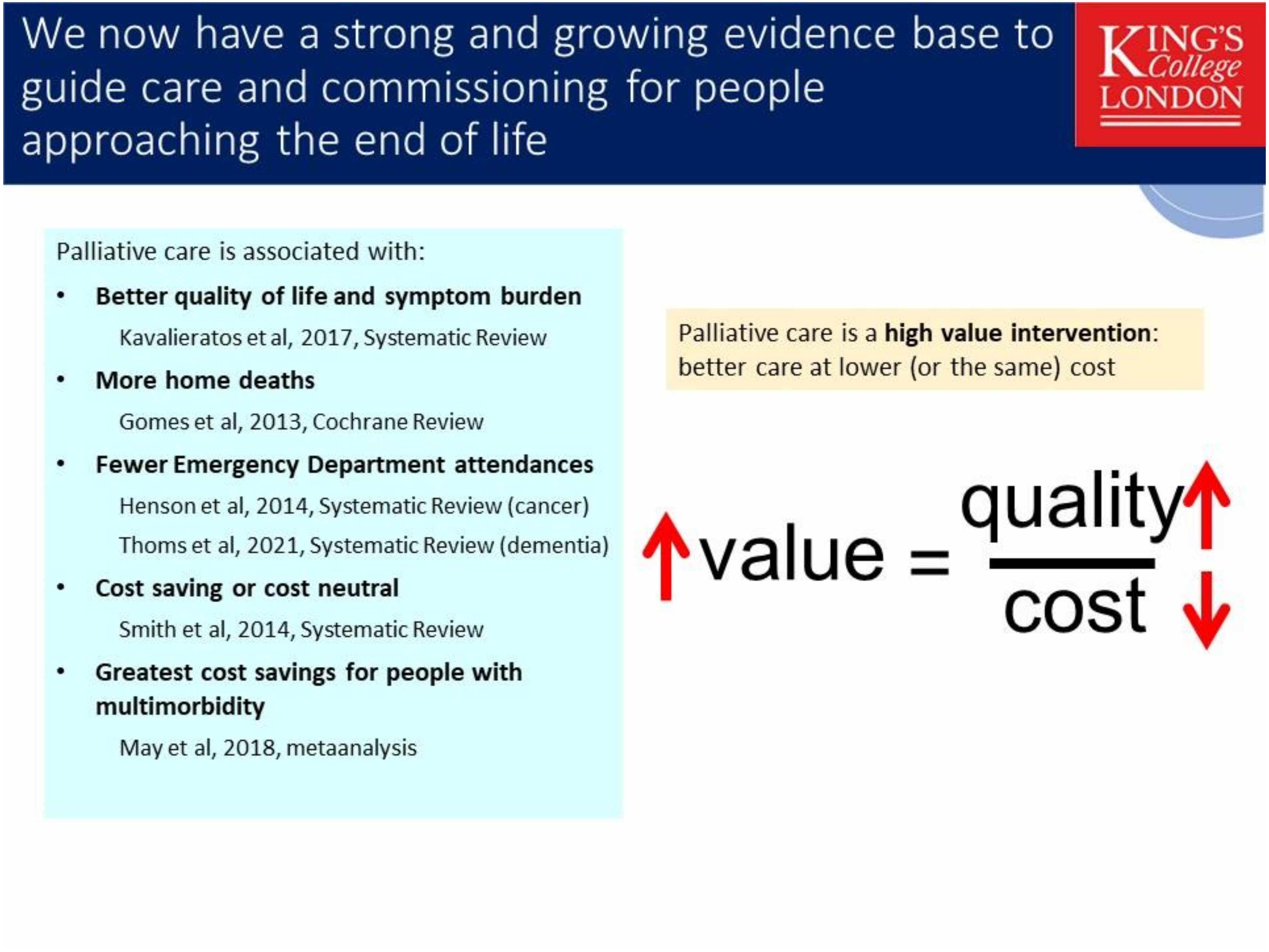
Honorary Consultant in Palliative Medicine
King's College Hospital NHS Trust

**www.csi.kcl.ac.uk**

# Palliative care: needs-driven, individualized care for people with life limiting illness

> 'We must somehow give everything we can to these people that says "you matter because you are you," everything to enable the patient to live up until he dies, and the family to go on living afterwards.'

**Cicely Saunders 'A death in the family: a professional view' British Medical Journal, 6 January, 1973, p30–31.**



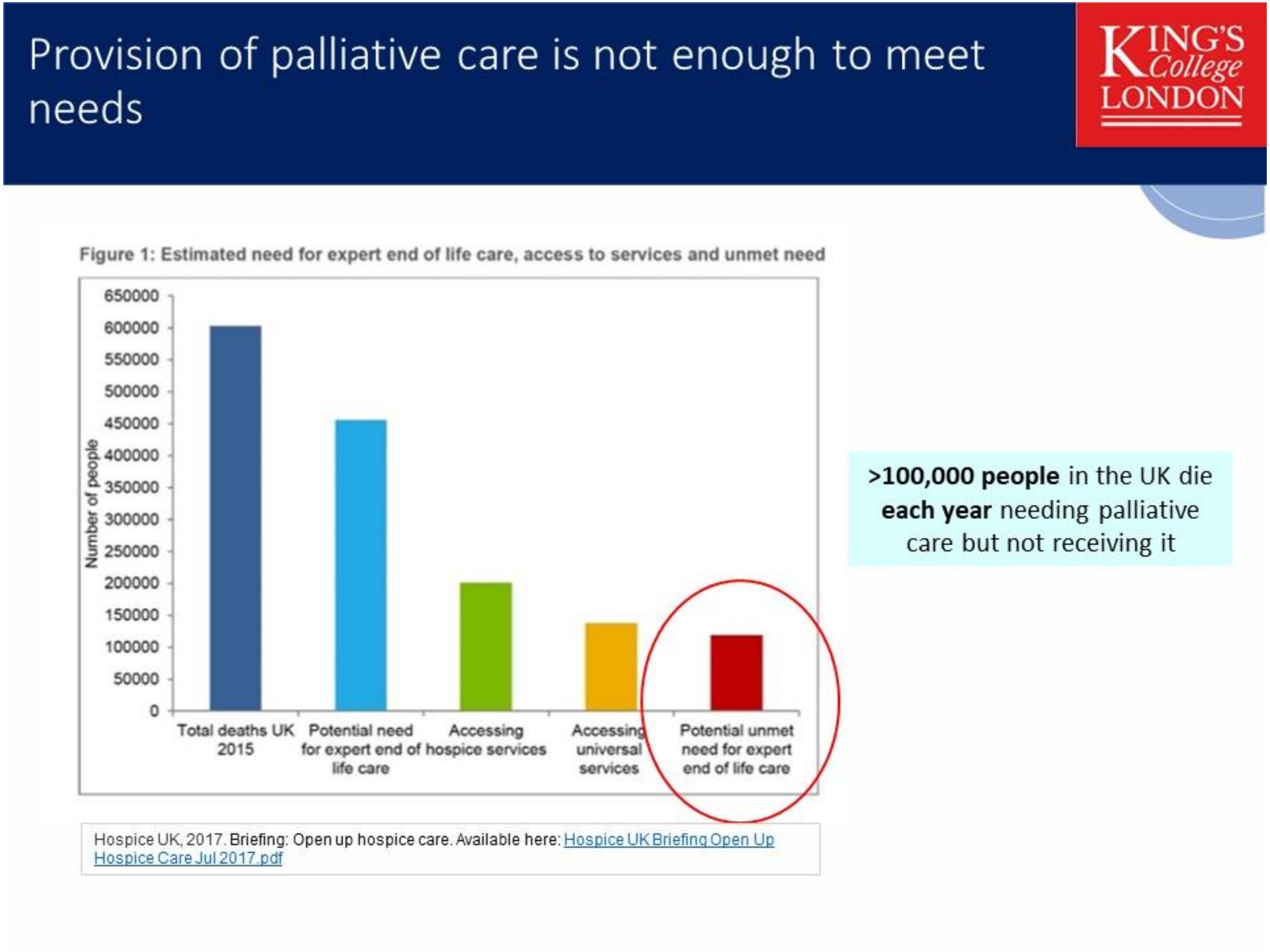
# We now have a strong and growing evidence base to guide care and commissioning for people approaching the end of life

Palliative care is associated with:

- **Better quality of life and symptom burden**
  Kavalieratos et al, 2017, Systematic Review
- **More home deaths**
  Gomes et al, 2013, Cochrane Review
- **Fewer Emergency Department attendances**
  Henson et al, 2014, Systematic Review (cancer)
  Thoms et al, 2021, Systematic Review (dementia)
- **Cost saving or cost neutral**
  Smith et al, 2014, Systematic Review
- **Greatest cost savings for people with multimorbidity**
  May et al, 2018, metaanalysis

Palliative care is a **high value intervention**: better care at lower (or the same) cost

$$\uparrow \text{value} = \frac{\text{quality}\uparrow}{\text{cost}\downarrow}$$

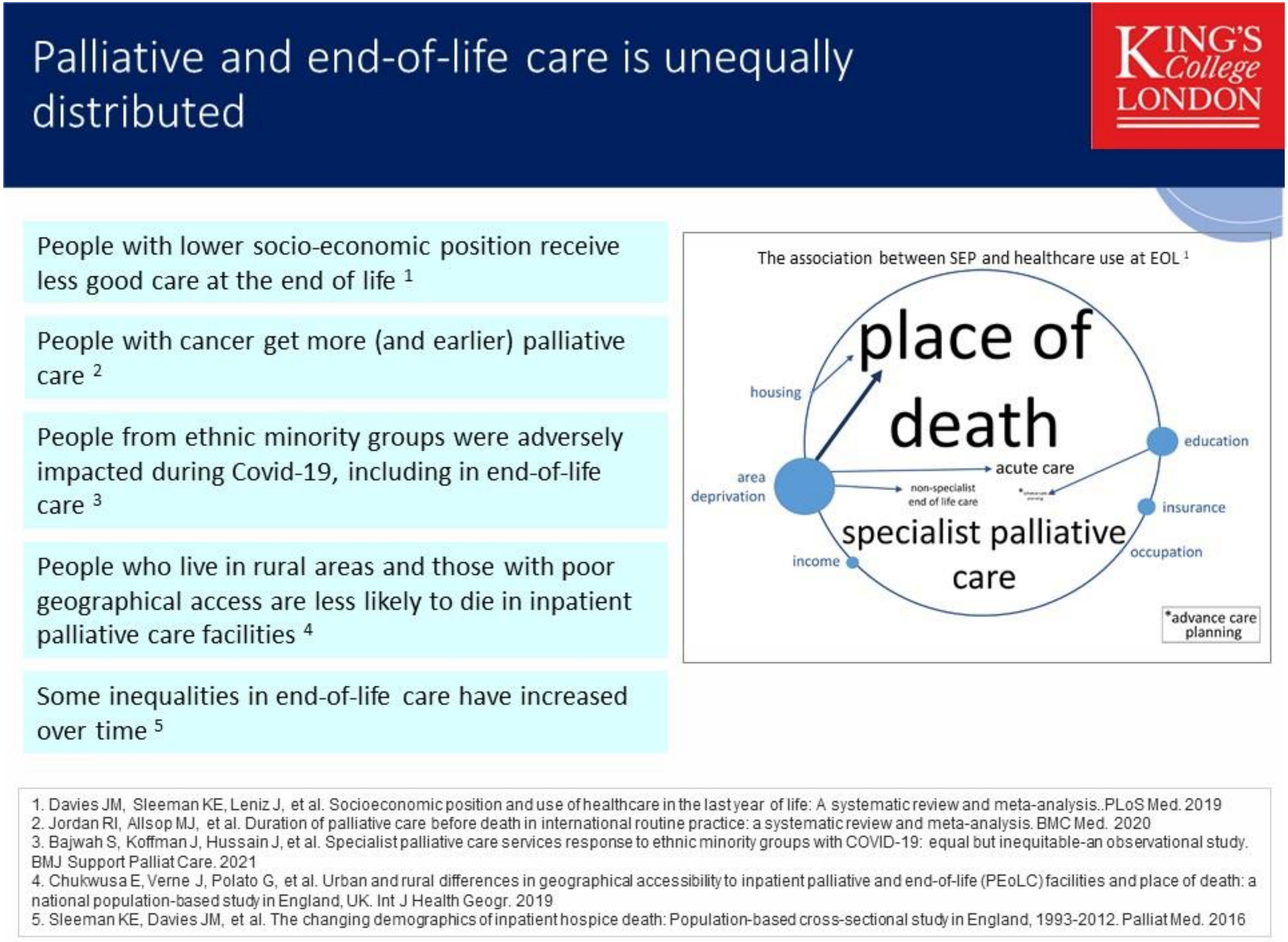


# Provision of palliative care is not enough to meet needs

Figure 1: Estimated need for expert end of life care, access to services and unmet need

Hospice UK, 2017. Briefing: Open up hospice care. Available here: Hospice UK Briefing Open Up Hospice Care Jul 2017.pdf

**>100,000 people** in the UK die **each year** needing palliative care but not receiving it



# Palliative and end-of-life care is unequally distributed

People with lower socio-economic position receive less good care at the end of life [1]

People with cancer get more (and earlier) palliative care [2]

People from ethnic minority groups were adversely impacted during Covid-19, including in end-of-life care [3]

People who live in rural areas and those with poor geographical access are less likely to die in inpatient palliative care facilities [4]

Some inequalities in end-of-life care have increased over time [5]

The association between SEP and healthcare use at EOL [1]

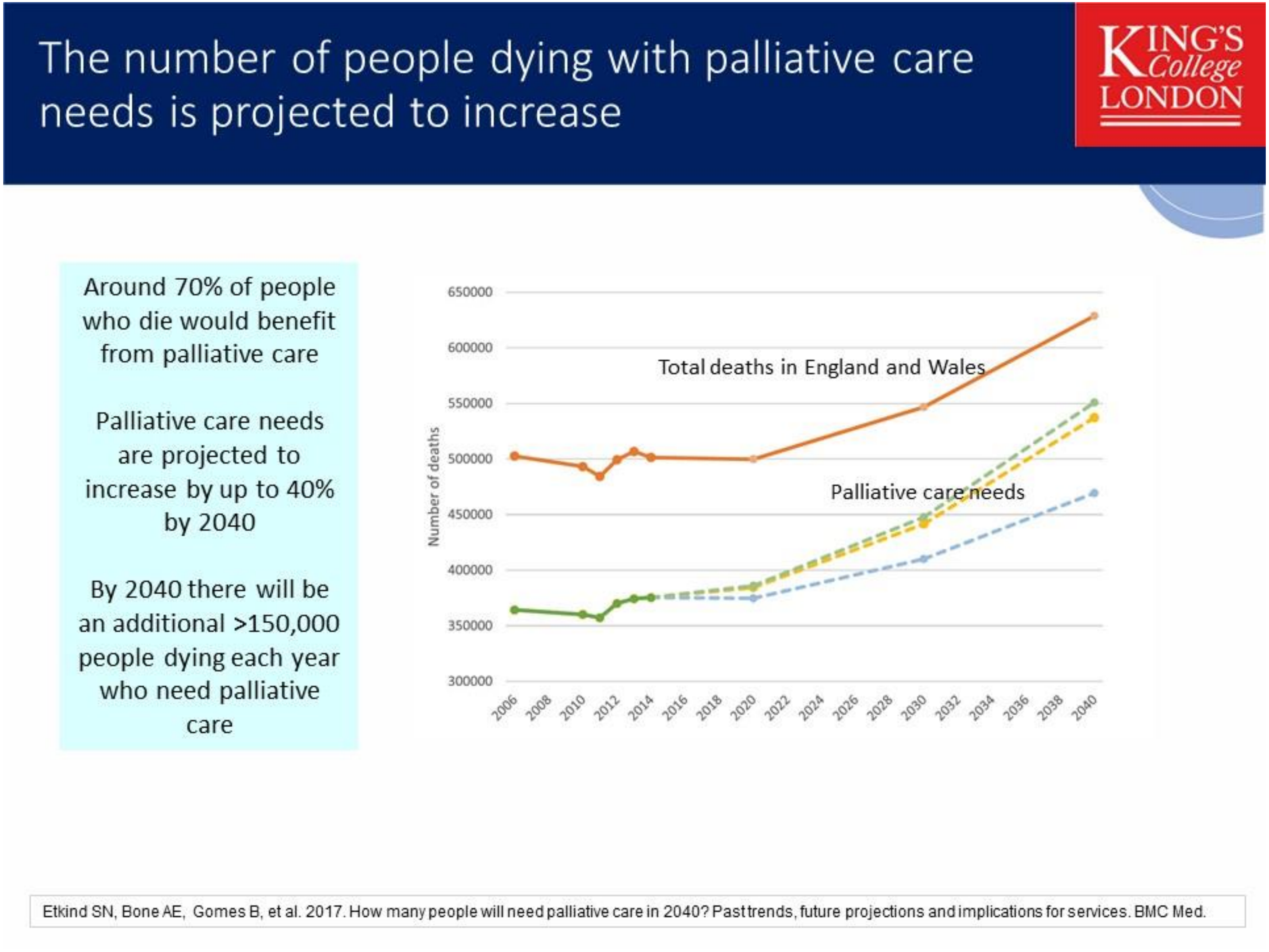
1. Davies JM, Sleeman KE, Leniz J, et al. Socioeconomic position and use of healthcare in the last year of life: A systematic review and meta-analysis. PLoS Med. 2019
2. Jordan RI, Allsop MJ, et al. Duration of palliative care before death in international routine practice: a systematic review and meta-analysis. BMC Med. 2020
3. Bajwah S, Koffman J, Hussain J, et al. Specialist palliative care services response to ethnic minority groups with COVID-19: equal but inequitable-an observational study. BMJ Support Palliat Care. 2021
4. Chukwusa E, Verne J, Polato G, et al. Urban and rural differences in geographical accessibility to inpatient palliative and end-of-life (PEoLC) facilities and place of death: a national population-based study in England, UK. Int J Health Geogr. 2019
5. Sleeman KE, Davies JM, et al. The changing demographics of inpatient hospice death: Population-based cross-sectional study in England, 1993-2012. Palliat Med. 2016

## For individual patients and carers, experiences of dying, death and bereavement are variable and can be poor

*"I could never have imagined such a difficult and heart-breaking experience. Our parting …. will live with me forever, devastatingly, for all the wrong reasons"*

Carer, England

Sleeman, K.E., Murtagh, F.E.M., Kumar, R., et al. Better End of Life 2021. Dying, death and bereavement during Covid-19. Research report. London (UK): Marie Curie. 2021 April.



# The number of people dying with palliative care needs is projected to increase

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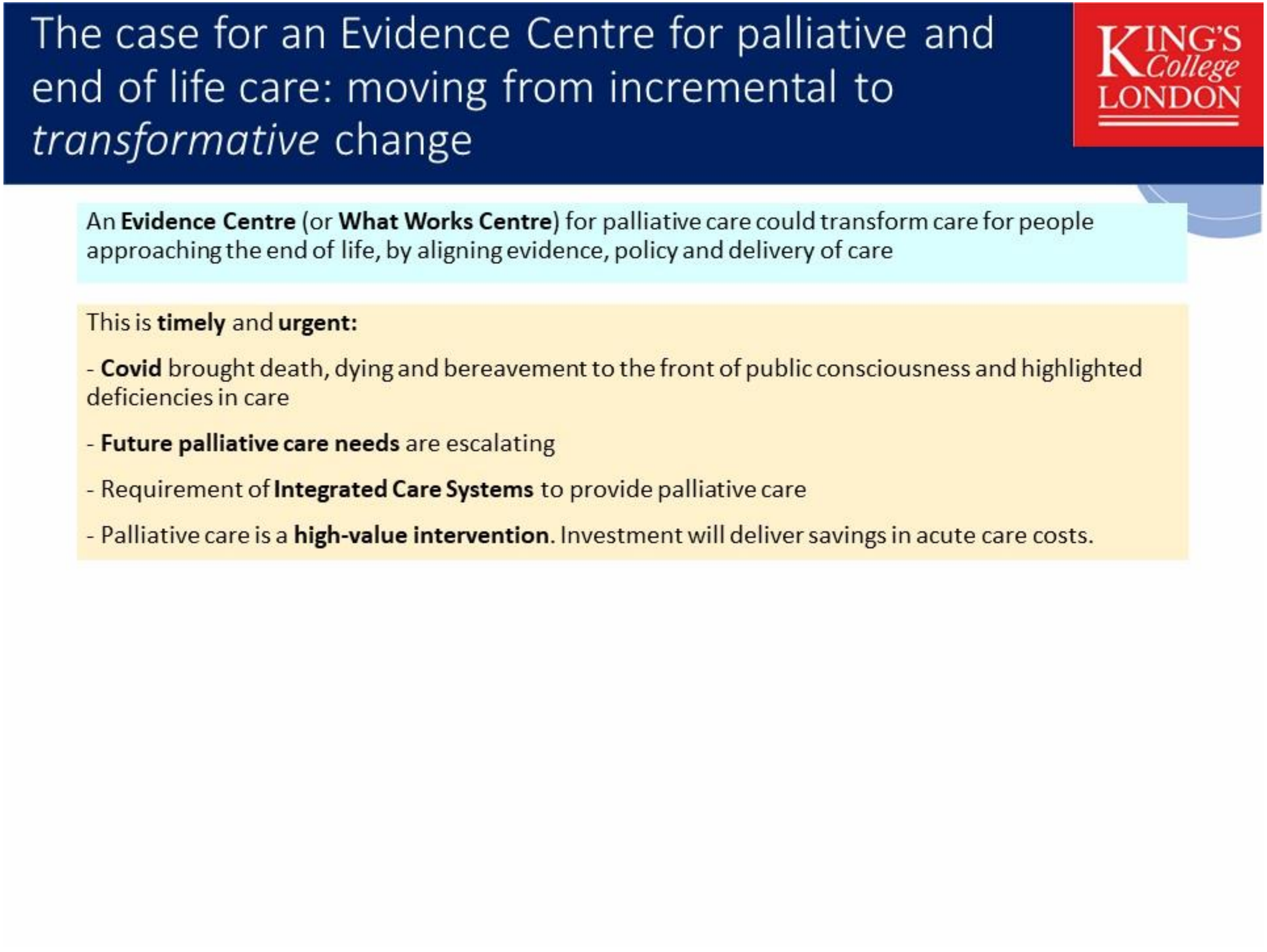
Around 70% of people who die would benefit from palliative care

Palliative care needs are projected to increase by up to 40% by 2040

By 2040 there will be an additional >150,000 people dying each year who need palliative care

Etkind SN, Bone AE, Gomes B, et al. 2017. How many people will need palliative care in 2040? Past trends, future projections and implications for services. BMC Med.

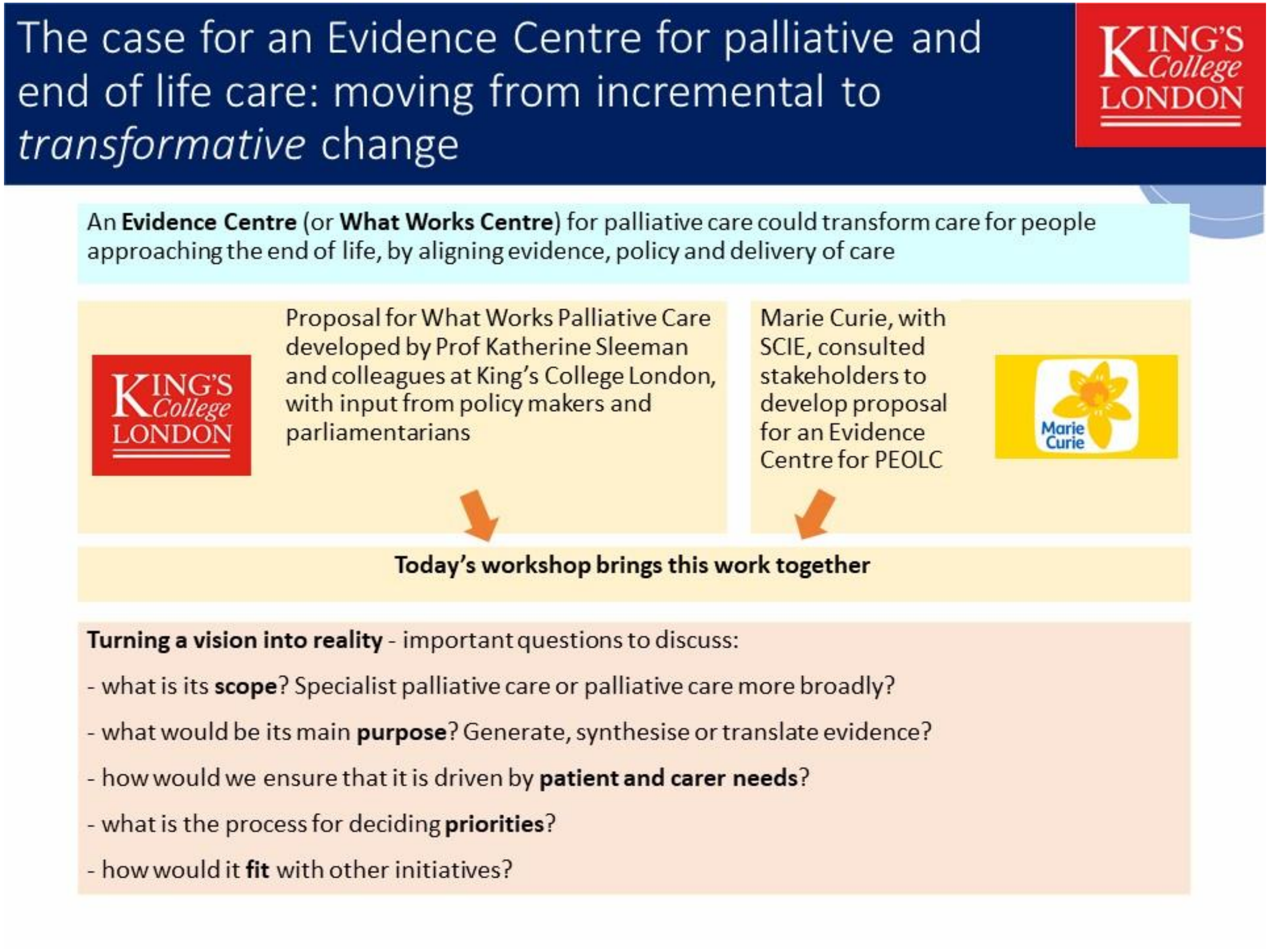


# The case for an Evidence Centre for palliative and end of life care: moving from incremental to *transformative* change

An **Evidence Centre** (or **What Works Centre**) for palliative care could transform care for people approaching the end of life, by aligning evidence, policy and delivery of care

This is **timely** and **urgent:**

- **Covid** brought death, dying and bereavement to the front of public consciousness and highlighted deficiencies in care
- **Future palliative care needs** are escalating
- Requirement of **Integrated Care Systems** to provide palliative care
- Palliative care is a **high-value intervention**. Investment will deliver savings in acute care costs.



# The case for an Evidence Centre for palliative and end of life care: moving from incremental to *transformative* change

An **Evidence Centre** (or **What Works Centre**) for palliative care could transform care for people approaching the end of life, by aligning evidence, policy and delivery of care

Proposal for What Works Palliative Care developed by Prof Katherine Sleeman and colleagues at King's College London, with input from policy makers and parliamentarians

Marie Curie, with SCIE, consulted stakeholders to develop proposal for an Evidence Centre for PEOLC

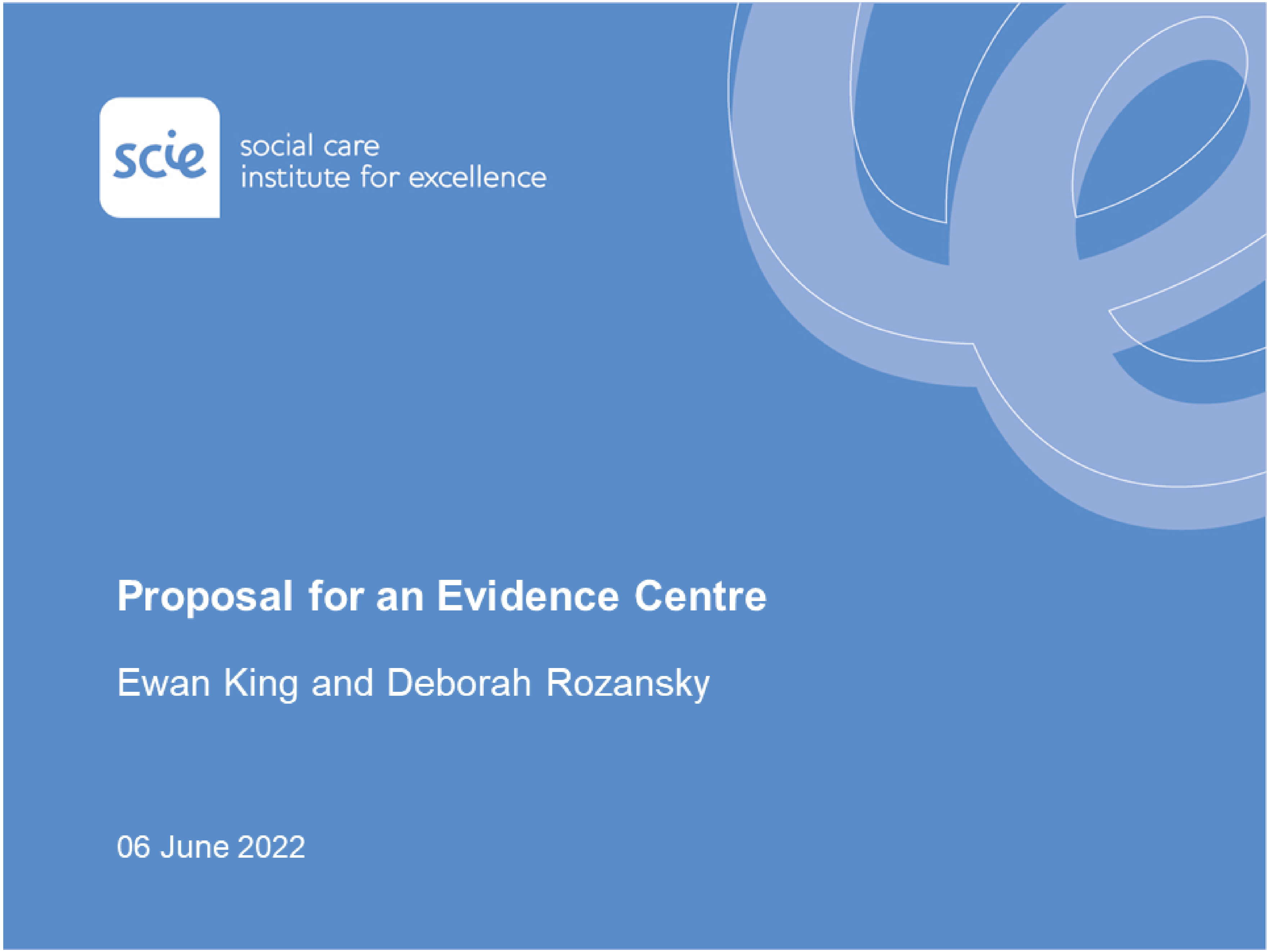
**Today's workshop brings this work together**

**Turning a vision into reality** - important questions to discuss:

- what is its **scope**? Specialist palliative care or palliative care more broadly?
- what would be its main **purpose**? Generate, synthesise or translate evidence?
- how would we ensure that it is driven by **patient and carer needs**?
- what is the process for deciding **priorities**?
- how would it **fit** with other initiatives?

Katherine Sleeman is the Laing Galazka Chair in palliative care at King's College London, funded by an endowment from Cicely Saunders International and Kirby Laing Foundation

katherine.sleeman@kcl.ac.uk



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# Proposal for an Evidence Centre

Ewan King and Deborah Rozansky

06 June 2022

## Background and methodology

SCIE were asked conduct a rapid scoping exercise, commissioned to explore the feasibility and potential role and operating model for a new Evidence Centre for Palliative and End of Life Care (PEOLC)

Key activities:

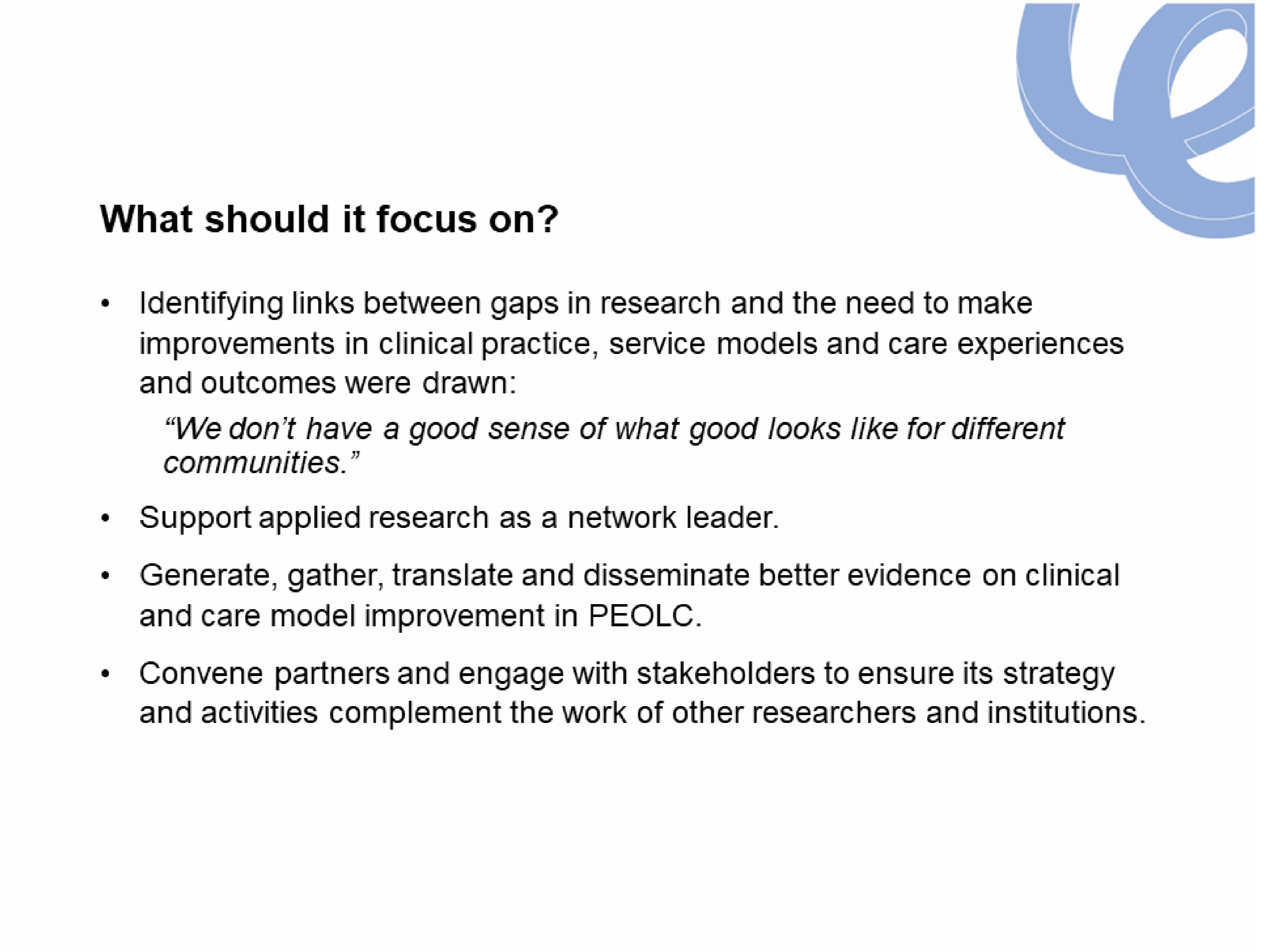
- Review of relevant policy and evaluative literature about evidence centres
- Exploratory sessions with Marie Curie
- Interviews with seven senior stakeholders from across the academic, clinical and policy landscape.
- Lessons from SCIE's experience of being part of the Incubator which established the What Works Centre for Children's Social Care, experience of delivering the NICE Collaborating Centre for Social Care involvement in ESRC / Health Foundation Funded IMPACT Centre.

## The Challenge

- Evidence base for PEOLC is underdeveloped, with significant gaps in the research necessary to support improvements in clinical practice, service model design, patient experiences and care outcomes.
- Research questions reflecting the needs of people with lived experience and their carers are not routinely prioritised.
- Evidence from existing research is often not translated into practice or widely disseminated, and innovations in practice are unsupported or not sustained.
- Current resources for research, research infrastructure and knowledge translation activities are limited and uncoordinated across the sector.

## Thoughts on its purpose

- Develop a shared framework and priorities for tackling critical research questions and evidence gaps
- Leverage this framework and shared priorities to develop new sources of research funding
- Facilitate the generation of new evidence through funding research collaboratives and initiatives with key partners and stakeholders
- Lead the synthesis and translation of evidence to support innovation and improvement: new models of care, clinical practice improvement, care delivery and care experiences
- Support the adoption and dissemination of evidence to accelerate improvements in the organisation, commissioning and delivery of PEOLC



## What should it focus on?

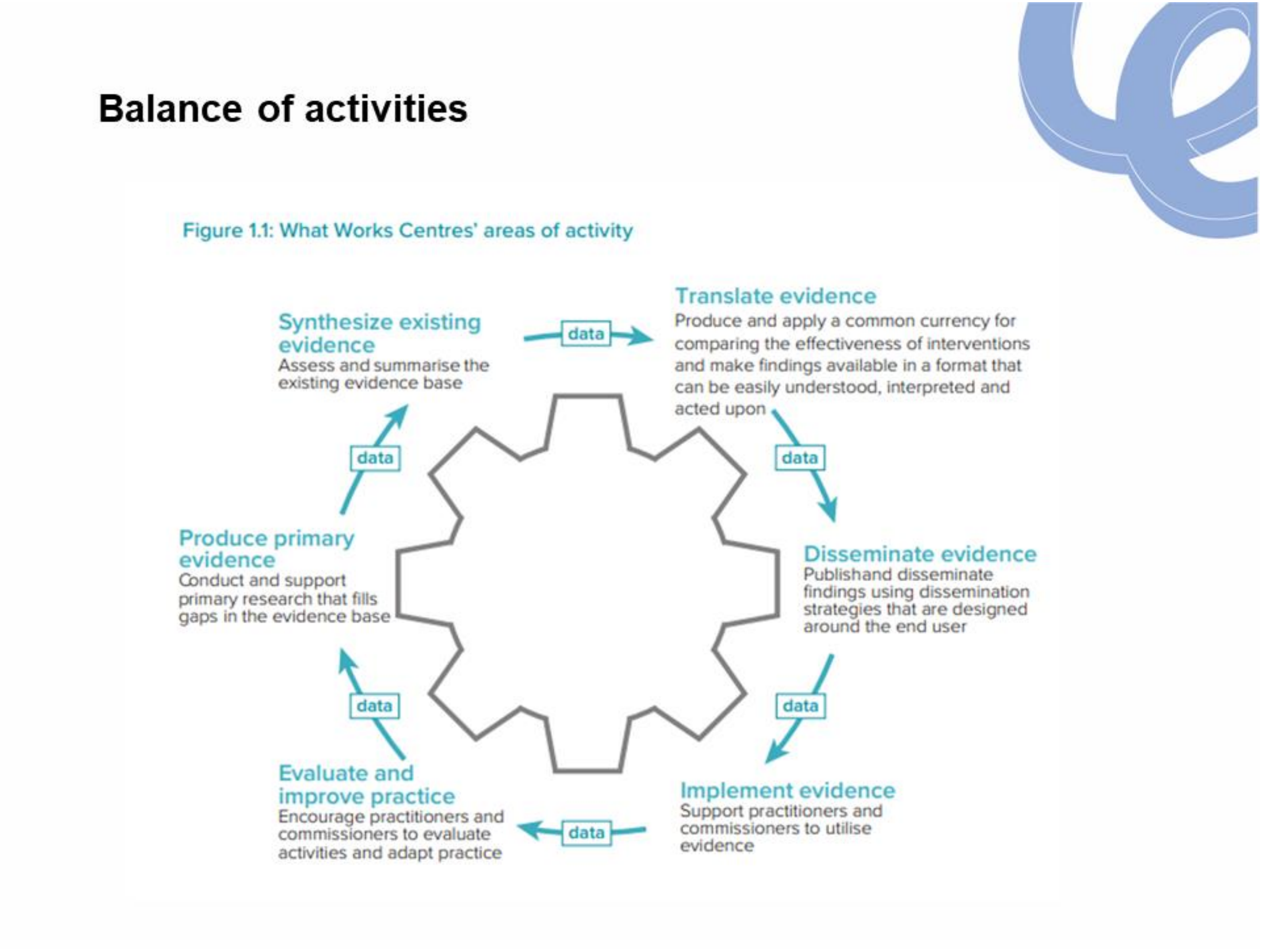
- Identifying links between gaps in research and the need to make improvements in clinical practice, service models and care experiences and outcomes were drawn:

  *"We don't have a good sense of what good looks like for different communities."*

- Support applied research as a network leader.
- Generate, gather, translate and disseminate better evidence on clinical and care model improvement in PEOLC.
- Convene partners and engage with stakeholders to ensure its strategy and activities complement the work of other researchers and institutions.

## What should it focus on? (2)

- Generate and draw on a broad range of evidence, including practitioner wisdom, the views of people with lived experience, and qualitative research.
- Generate evidence on effective commissioning and how to develop and scale innovative models of care.
- Testing, evaluating and informing the roll out of new models of PEOLC. Ensuring that contributions of people with lived experience and their carers should be instrumental
- Share evidence with governments and the NHS to inform policies that further the adoption and diffusion of research insights and innovation.



## Balance of activities

Figure 1.1: What Works Centres' areas of activity

**Translate evidence**
Produce and apply a common currency for comparing the effectiveness of interventions and make findings available in a format that can be easily understood, interpreted and acted upon

**Disseminate evidence**
Publishand disseminate findings using dissemination strategies that are designed around the end user

**Implement evidence**
Support practitioners and commissioners to utilise evidence

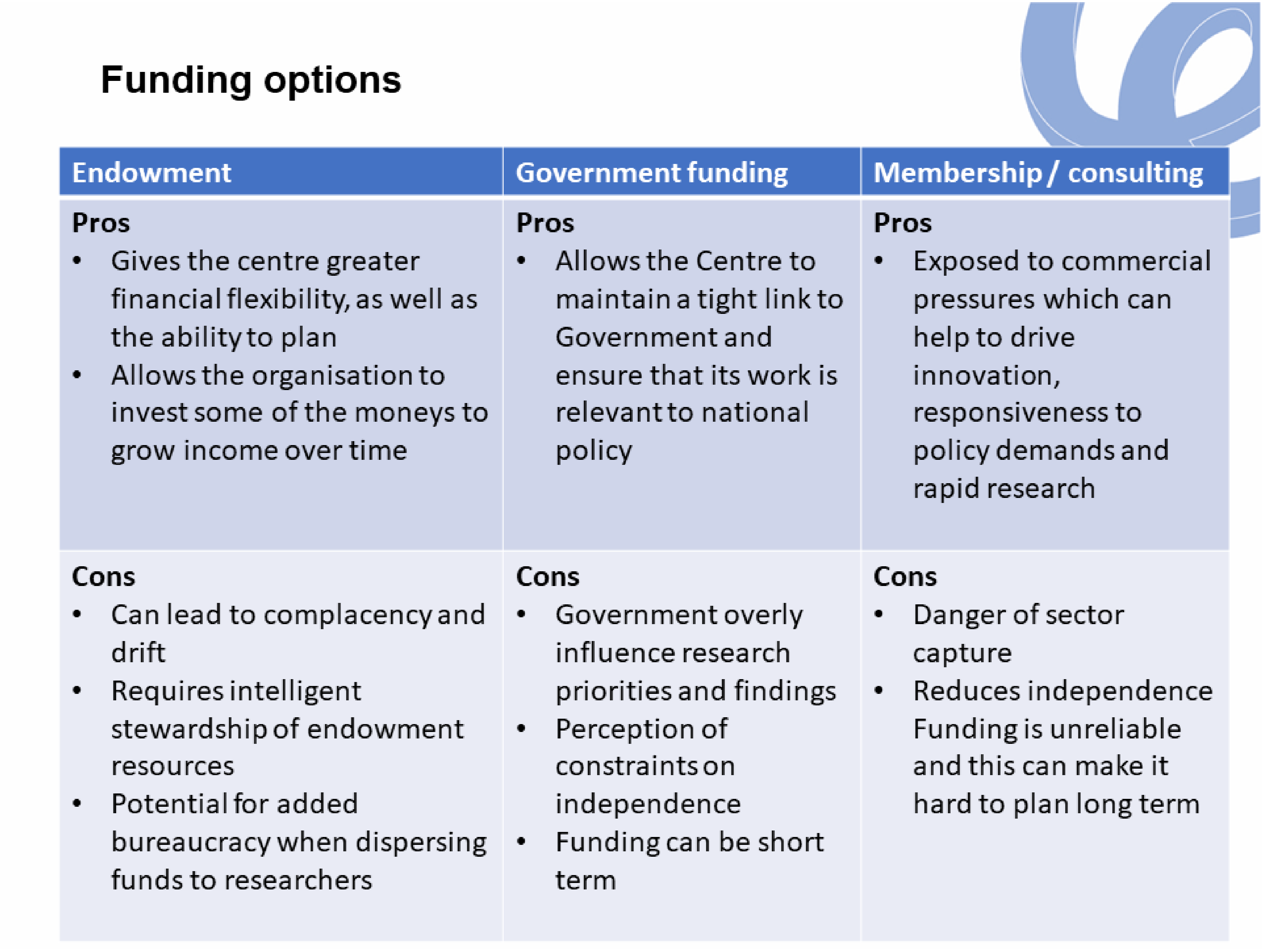
**Evaluate and improve practice**
Encourage practitioners and commissioners to evaluate activities and adapt practice

**Produce primary evidence**
Conduct and support primary research that fills gaps in the evidence base

**Synthesize existing evidence**
Assess and summarise the existing evidence base

## Governance principles

- Independence from funders
- Political independence
- Accepting that governance might change over time
- User and sector involvement: Involve the centre's users of the research from the outset to inform organisational design and governance
- Involving a broad range of experts: Mix of expertise, including research and behaviour change:
- Avoiding organisational capture by a particular sector:
- Freedom to publish
- This decision cannot be changed if findings are unfavourable or difficult.

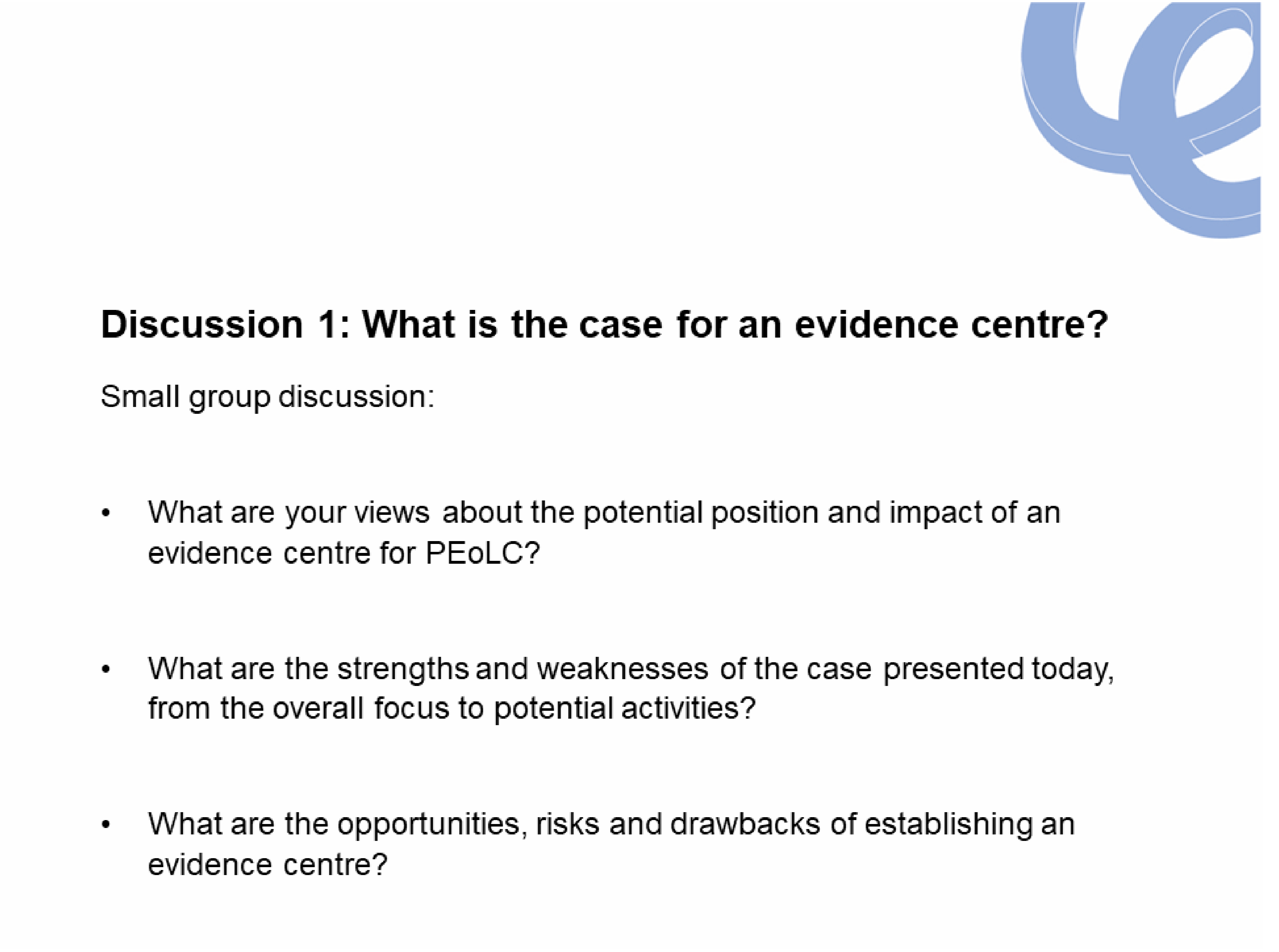


## Funding options

| Endowment | Government funding | Membership / consulting |
|---|---|---|
| **Pros**<br>• Gives the centre greater financial flexibility, as well as the ability to plan<br>• Allows the organisation to invest some of the moneys to grow income over time | **Pros**<br>• Allows the Centre to maintain a tight link to Government and ensure that its work is relevant to national policy | **Pros**<br>• Exposed to commercial pressures which can help to drive innovation, responsiveness to policy demands and rapid research |
| **Cons**<br>• Can lead to complacency and drift<br>• Requires intelligent stewardship of endowment resources<br>• Potential for added bureaucracy when dispersing funds to researchers | **Cons**<br>• Government overly influence research priorities and findings<br>• Perception of constraints on independence<br>• Funding can be short term | **Cons**<br>• Danger of sector capture<br>• Reduces independence Funding is unreliable and this can make it hard to plan long term |

## Options for set up

- Incubation / Discovery Phase – WWC Children's Social Care / IMPACT
- Hosted in organisation
- Shadow board, interim CEO



## Discussion 1: What is the case for an evidence centre?

Small group discussion:

- What are your views about the potential position and impact of an evidence centre for PEoLC?
- What are the strengths and weaknesses of the case presented today, from the overall focus to potential activities?
- What are the opportunities, risks and drawbacks of establishing an evidence centre?

# Comfort break

# Discussion 2: How might we develop the idea further?

Small group discussion (3 parts):

## 1. Purpose and audience

What should the primary aims of Centre be?

Who are the primary users of the Centre's evidence?

How do we engage the sector, people with lived experience and other stakeholders in shaping the Centre's priorities?

# Discussion 2 (con.)

## 2. Governance and leadership

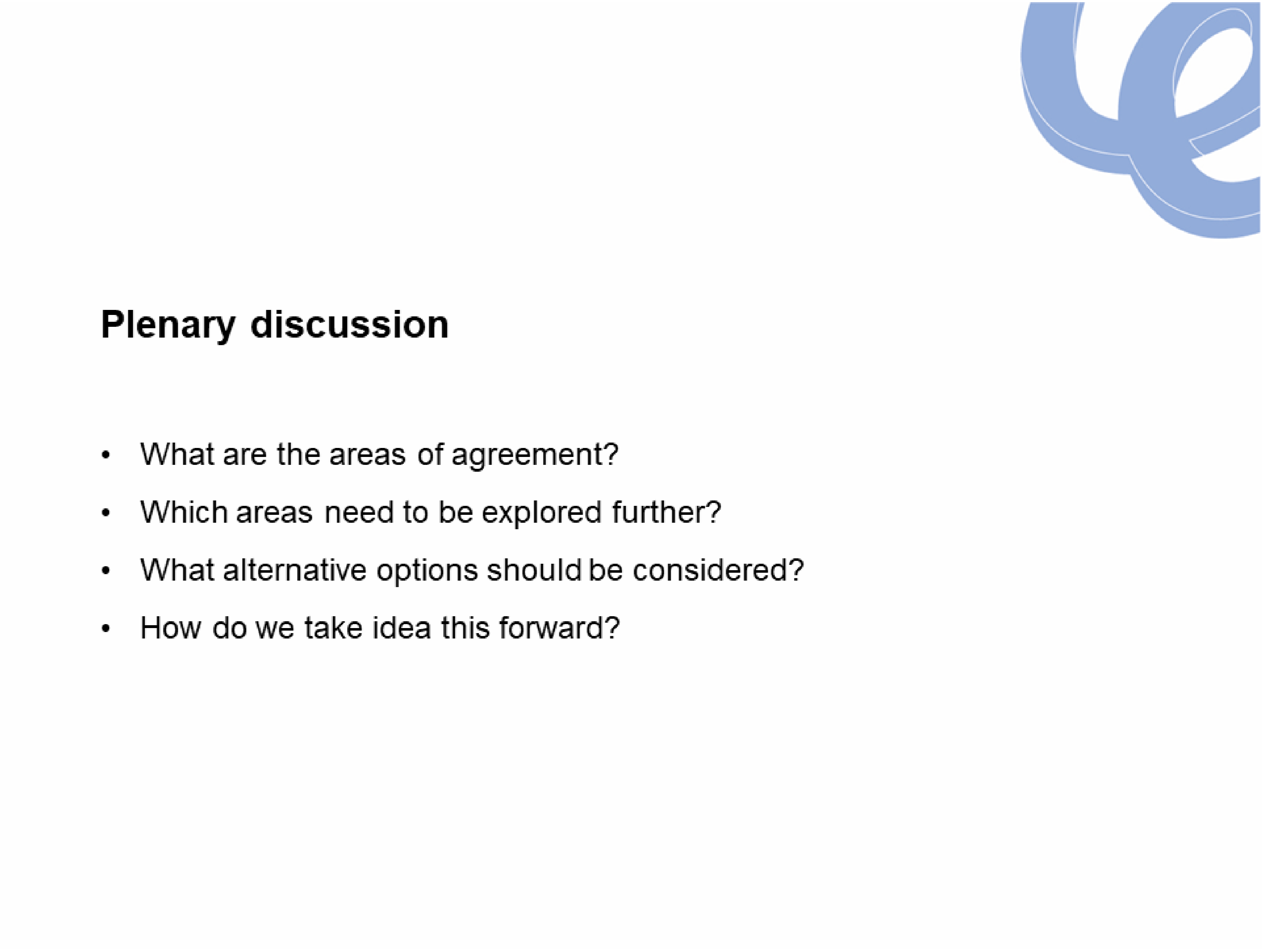
Options for governance: Which option seems most suitable, and why?

How might we develop the leadership of the centre?

## 3. Funding model

Options for a funding model for the Centre: What are your views?

What are the drawbacks and opportunities of different models?



## Plenary discussion

- What are the areas of agreement?
- Which areas need to be explored further?
- What alternative options should be considered?
- How do we take idea this forward?

# Thanks, concluding remarks and next steps