

Identifying and achieving preferences for place of care and place of death at the end of life:

Understanding the impact of this CSI research stream on UK policy, service development and public debate

A short impact review: making a qualitative contribution to the discussion

Steve Dewar

13th May, 2013

**Steve Dewar
Associates**

Table of Contents

Executive Summary.....	3
Introduction	5
Understanding the role of research evidence in public policy.....	6
<i>Emerging and overarching political ideas</i>	<i>7</i>
<i>Existing research to crystallise and encapsulate.....</i>	<i>7</i>
<i>Influential individuals who believe the idea to be right.....</i>	<i>8</i>
<i>Opportunity to do more for less.....</i>	<i>9</i>
<i>Momentum.....</i>	<i>9</i>
An understanding and illustration of the influence of this research stream on UK public policy in End of Life Care	11
An understanding and illustration of the influence of this research stream on UK national strategies for improvement in End of Life Care	14
An understanding of the influence of this research stream on major national UK charities, transforming their public profile and their organisational objectives	17
An understanding of the influence of this research stream on the public debate concerning death and dying in the UK	19
How participants in this short review felt that future work should be orientated in order to sustain and deepen impact.....	20
Appendix A: A note on the constraints of the short review	22
Appendix B: A note on Review Participants	23

Executive Summary

Our analysis of the published documentation alongside discussions with a range of stakeholders in end of life policy and service development has led to five evidence based statements about the impact of this CSI research stream in the UK. These are given below.

1. There is no doubt that early work on the identification of public preferences in relation to preferred place of death, compared to data on actual place of death, played a significant part in the development of UK public policy in end of life care.

The early research of the Institute although not sufficient to trigger public policy change on its own was one of a small number of necessary factors that drove and sustained policy change over a decade.

2. The CSI work was instrumental in a process that set the achievement of preferences as the dominant framework for service development and improvement in end of life care. This triggered several cycles of service improvement across the system aimed at developing an understanding of how to better design and develop more effective and cost-effective models of care.

The work of the Institute was instrumental in initiating service development work. However, achieving impact on the details of a range of service development programmes is a highly complex task. Undertaking research to influence detailed service delivery is difficult and often highly contested; our Review Participants did not see the ongoing work of the CSI as being significant at this level.

3. There is no doubt that this research stream played a significant role in changing the approach of some major UK national charities working in end of life care. It transformed their approach to fundraising and service development as well as influencing their culture of care-giving. It also transformed the approach of some major UK charities to campaigning and influencing public policy.

When it comes to this area of impact, the on-going work of the Institute can be considered to be of primary importance. The data suggests that these changes would not have occurred without this stream of research and the influence it had on the strategic thinking of key individuals and organisations.

4. There is no doubt that early work on the identification of public preferences in relation to preferred place of death compared to data on actual place of death, played a significant part in providing crucial evidence with which individual UK policy makers and UK organisations could engage with the

public in debates over death and dying – debates that had previously not occurred.

The early CSI research was one key source of evidence that enabled key figures to embark on public debate and discussion of death and dying in a new way. Although other sources of research and evidence were referred to and can be seen in the public record, there is no doubt that the work of the Institute was often dominant in the use of evidence over preferences and that this often drove the public debate.

5. It is clear that there is a high level of interest in the on-going work of the Institute and participants in this short review presented a consensus over the need to continue the work and to take forward a focus on a deeper understanding on how preferences for particular sub-groups of the population living with life-shortening illness change over time; may be 'traded off' against other preferences; and may be best met by new forms of service organisation or delivery.

Introduction

This short report has been commissioned and delivered by a researcher independent of the Cicely Saunders Institute, King's College London.

The aim of the work has been to make a robust contribution to the understanding of the impact of a stream of research work from the Institute on 'identifying and achieving preferences for place of care and place of death at the end of life'.

The details of this research stream are detailed in the 'REF Place of Care and Place of Death Impact Statement'. This work consists of multiple research outputs from the late 1990's through to 2012.

In undertaking the review two sources of data have been considered:

- i) A review of the research, policy, and service development documentation across the field of end of life care; as well as reports in the public media; and
- ii) A series of six interviews with policy makers, end of life charity Chief Executives and service development leads in end of life care.

A number of themes were clear from an overview of both data sources and these form headings in this report. In brief, they are as follows:

- An understanding and illustration of the influence of this research stream on UK public policy in End of Life Care;
- An understanding and illustration of the influence of this research stream on UK national strategies for improvement in End of Life Care;
- An understanding of the influence of this research stream on major national UK charities, transforming their public profile and their organisational objectives;
- An understanding of the influence of this research stream on the public debate concerning death and dying in the UK;
- How participants in this short review felt that future work should be orientated in order to sustain and deepen future impact.

In these sections of the report the themes are explored and data from the short review presented and assessed. However, before this the report considers the complex nature of the processes at work. In particular, it is useful to consider a framework that might help understand the question of impact in relation to policy development.

Understanding the role of research evidence in public policy

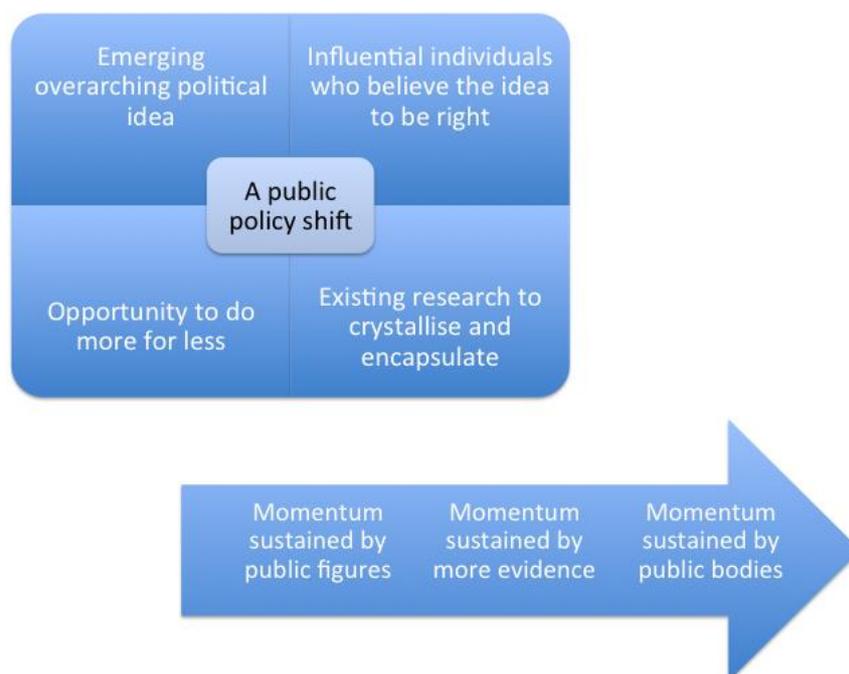
The title for this section of the report could support a programme of long-term research, however in the context of this short impact review the intention is to share the emerging themes that have arisen from the discussions with our Review Participants. These reflections from a small number of key players in the development of UK initiatives in end of life care over the last 10 years set the scene for the subsequent assessment of impact in relation to the work of the Institute.

When asked to describe the impact of the work of the Institute on the development of public policy in the UK all participants in this review commented on the complex process of policy development and the partial, although important role of research evidence in that process.

All our participants saw the focus on end of life care and the achievement of preferences at the end of life, particularly in relation to choice over place of death, as a significant component of the wider development of 'choice'. This was in their view an emerging and dominant organising principle in the public policy framework for public service reform and improvement.

There was a remarkable degree of agreement over some aspects of the dynamics in play. All those participants with a degree of personal insight into the process provided a perspective that broadly supported the notion that there were a number of components in play when significant policy development took place.

This agreement revolved around four components that they suggested needed to be in place to enable the development of new public policy – of which only one relates to the evidence. The diagram below illustrates.



Emerging and overarching political ideas

In relation to the undoubted shift in public policy that put the achievement of preferences at the end of life to the fore a number of participants in the review pointed to work in the early 2000's as being significant.

Review participants talked about the way in which three streams of thinking at different levels within the system came together:

- i) The application of choice as a political instrument for reform of the public services;
- ii) The application of choice in the field of health care reform in particular; and
- iii) Thinking on the value of choice as a tool for improving end of life care.

The following comments from review participant 2 (RP2) illustrates this well: *"In 2002 those involved in the highest levels of policy making became interested in pushing patient views thought the idea of choice - they were trying to bring some of the commercialisation of the private sector into the public sector."* (RP2)

"Choice really started with the NHS Plan 2000. It came from the Plan that is where the idea came from.... and I remember discussing it personally with the Secretary for State." (RP2)

"He thought that in order to get change we would have to lever a different dynamic than the politicians or the managers or the health professionals. He wanted to create a triangle where managers and health professionals had to work alongside patients: in order to bring about a different way of making change happen." (RP2)

"I was summoned and put in charge of this exercise [identifying possible area of patient choice] and when picking themes I remember [name] was clear that end of life was an area badly delivered in the health service and needing a fresh look at..." (RP2)

Existing research to crystallise and encapsulate

However, participants in the review did see research as important in the dynamic that drove policy change, even if it's role was not 'game-changing'. Without evidence to support the emerging political idea some review participants did not think that the process would have been complete or would have developed so much energy.

"Evidence is important. It's important when the evidence really suggest something isn't going to work - people don't go on in the face of that type of evidence. And it's important when it supports an idea that people are already pursuing - giving it momentum and credibility." (RP2)

When asked about how they became aware of choice and the achievement of patients choices about care at the end of life as an important concept that might play a role in public policy, participants always referred to the research evidence and some specifically referred to the work undertaken by the Institute.

"I guess Irene's work. I didn't feel it came from anywhere else. That early work was to my mind the driver of the idea that our understandable choices about where we wanted to die were not being met." (RP4)

"Yes these choices [in end of life care] were supported by survey work and that was important." (RP2)

However, participants consistently placed this significant evidence in the context of a multi-faceted process.

"Establishing choice at the end of life was driven by this political idea, and then a look at the evidence – "ah-ha here is an obvious choice and one that people tell us they want." (RP2)

Even while there was acknowledgement of the necessary role of research evidence in the process – to support the case for change and to encapsulate the need to shift policy, there was some cynicism about the role of research as an actual driver of policy development.

"But evidence based policy-making. Well there used be a joke in my team. When I came up with a good idea they would say "Well, that would work well in practice: but will it work in theory?" (RP2)

Influential individuals who believe the idea to be right

All review participants highlighted this crucial aspect of the public policy process. In relation to the emphasis on the achievement of preferences at the end of life participants commented on the vital role of individuals in driving the process of change.

"Policy making is a political and personal process - the actual individuals pushing this stuff - when you are doing it, it is driven as much by your personal judgement about what is right. It is a kind of mix of the zeitgeist in terms of the politics and the individuals." (RP2)

"It was a three-way partnership of individuals that changed the landscape, with the End of Life Czar coming together with his mate and for once the Department of Health, a major charity and a celebrity coming together and people then "got it" - all the way up to the prime minister, people then just "got it." (RP4)

"One of the defining moments was the appointment of a National End of Life Director. That gave it leadership. At the time the Department of Health was trying to relieve itself from the direct delivery of health care and encourage more

localised decision making systems and leadership was vital to making this happen. Leadership at all levels in the system. Such as the focus adopted in the South West of England where end of life care was made a priority.” (RP1)

Opportunity to do more for less

Review participants also commented on one further aspect of the dynamic in policy making in this area, the notion that the policy idea had to enable government to ‘do more for less’. Although this was not the only criteria against which a political idea that might reshape public policy would be judged, participants in this review did comment that this was a necessary (if not sufficient) criteria and that the overarching political story, of then as well as now, emphasised the need to find opportunities to improve cost efficiency in public sector service delivery.

A number of participants in the review drew parallels between this confluence of forces in relation to choice at the end of life and the potential for further integration between health and social care to also generate similar momentum over future years (with a similar end of life care facet to the policy drive). This may be useful to note in relation to setting the future research agenda in the field.

“If we look at the current UK interest in integration of health and social care we find the same combination of ideas that we found in the consideration of choice at the end of life. A good simple idea combined with good economic sense. That gives it legs.” (RP4)

Momentum

The other concept that participants in this short review of impact wished to highlight was ‘momentum’. In the view of a number of participants the shift in public policy concerning choice at the end of life, even if it had not been primarily driven by research, was sustained and given momentum by the on-going work, from the Institute and others.

Review participants felt that this momentum often came from the research evidence, not only in its original form but in the way that ‘champions of the cause’ then subsequently used new data to promote, remind or articulate the importance of improving care in this area. Evidence was seen as having an important role here and the Institute was seen as one of few key and credible sources for that data.

“Although some did not like it because it focused on the where rather than the how, the thing is that the public got it. They understood the question: “do you want to die in a hospital or at home” and when you could use the evidence to tell them that most of them would die in a hospital, and that there wasn't the room to die in a

hospice, and that we couldn't support them to die at home, then they could hardly believe it." (RP4)

An understanding and illustration of the influence of this research stream on UK public policy in End of Life Care

The commentary given by Review Participants (summarised in the section above) makes it clear that it is far from straightforward to identify and map a clear chain of influence from research evidence to the development of policy in the UK.

However, the Review Participants were clear about the role of the Institute's early work in providing the key supporting evidence for the development of policy in this area. They were also in agreement about the catalytic role that the work had in supporting a policy initiative that not only re-shaped end of life care in the UK, but supported a series of sustained policy and development initiatives over a decade.

"It is interesting how the ideas represented in that early work were turned by the current political discourse into 'choice' and all that came with it. It moved from a set of material driven by data into a wholly different sphere." (RP5)

Similarly, a review of the policy documentation alongside this commentary from Review Participants provides a clear picture of how the CSI work was a key element in the development of policy at that time.

Diagram 1 illustrates the dynamic and sustained growth of this policy initiative and demonstrates the connections between these stages of policy development and the chain of reference between the work and early CSI publications. This connection is confirmed by the commentary of participants in the review.

"The early evidence gave rise to recognition that not enough knowledge and information was available about what was really happening." (RP1)

"The evidence of the gap between expressed and actually achieved preferences prompted a second wave of questions." (RP1)

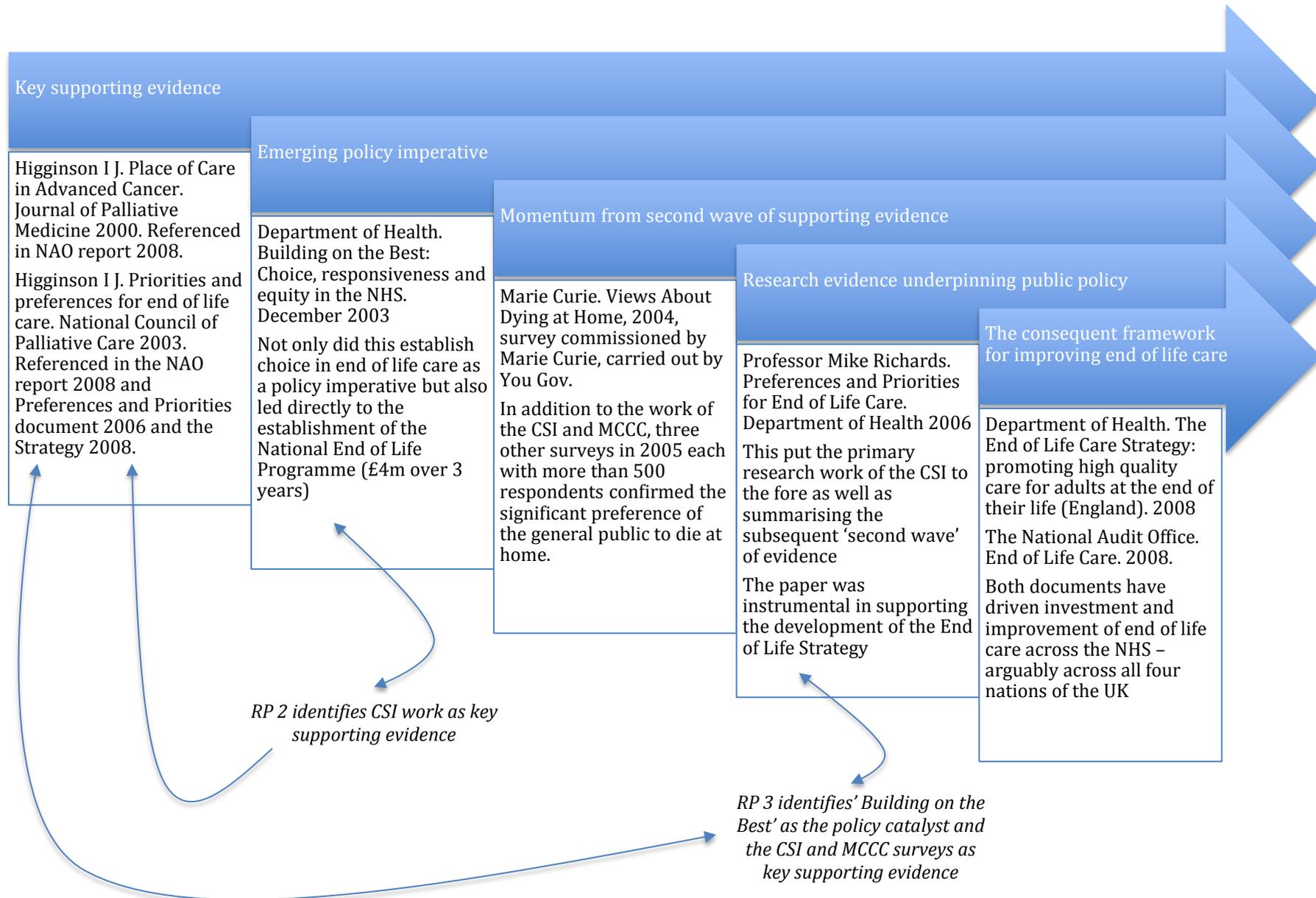
"The work on where people die: as far as the NAO was concerned this section all really referenced the King's work" (RP1)

Impact Statement

There is no doubt that early work on the identification of public preferences in relation to preferred place of death, compared to data on actual place of death, played a significant part in the development of UK public policy in end of life care.

The early research of the Institute although not sufficient to trigger public policy change on its own was one of a small number of necessary factors that drove and sustained policy change over a decade.

Diagram 1: CSI research as key supporting evidence in the development of public policy



An understanding and illustration of the influence of this research stream on UK national strategies for improvement in End of Life Care

Review Participants were clear that the Institute's work also played a catalytic role in supporting initiatives for service development in End of Life Care. The work of the Institute was central in established a key indicator for this improvement effort – recording and meeting preferences for care and place of death at the end of life.

It is clear that both the political momentum behind the concept of choice and the need to find frameworks and indicators that could allow the Department of Health to guide rather than control development across the county, helped create the environment where this data could take centre stage. But without the supporting evidence to show the discrepancies between preferences and outcomes, it is arguable that the service development agenda could have taken a very different shape.

As one of the Review Participants commented: *“The desire to give people choice at the end of life became a fixed statement and drove the energy behind implementing a policy and measuring performance.”* (RP1)

Diagram 2 illustrates the dynamic and sustained growth of this focus on service development and demonstrates the connections between these stages of the service development cycle and the chain of reference between the work and CSI publications. This connection is confirmed by the commentary of participants in this short review.

However, the impact of the CSI outputs on 'ground level' service development is contested. For some it transformed the agenda but for others it didn't quite provide the data around which new services could be organised.

“I have regularly used the work of Higginson and Gomes on the factors that influence home death - particularly the importance of the capacity of the family to be involved and to help in delivering the care needed. I have used this internally and externally to remind people of the value and the need to support carers and to help demonstrate why we use social workers and why we use welfare workers.” (RP5)

“Once I am interested in a story line then I will take a closer look. For me one absolute tipping point was in 2011, when I was exposed to the work on preferences compared to actual place of death for particular groups in England - really fantastic stuff, eloquent and readable – and linked to the strategy. For me it highlighted the preferences of older people - how they wanted to get into hospice

but didn't get into hospice. I was struck by the disparity between my beliefs and this data.” (RP 6)

“As evidence it is really helpful, in the sense that you were always told to reference your thinking and the stream of work from the Institute is quoted regularly but could it do more and is it possible for it to better match our service development needs?” (RP5)

However, whatever the mixed view of how applicable some of the research outputs may have been to the task of service development, there was no doubt that the Institute was central to a process that brought service improvement of end of life care to the fore.

Of all the comments made by Review Participants the following illustrates how dramatically the environment changed in 2008.

“I remember attending the launch of the Darzi Review, I think it was in 2008 and in this big hall participants were directed to different rows - there were different rows for different disease charities, heart, cancer and so on and then there was an enormous row with a label on each seat that said end of life care. It was at that point that I knew we had made it!” (RP4)

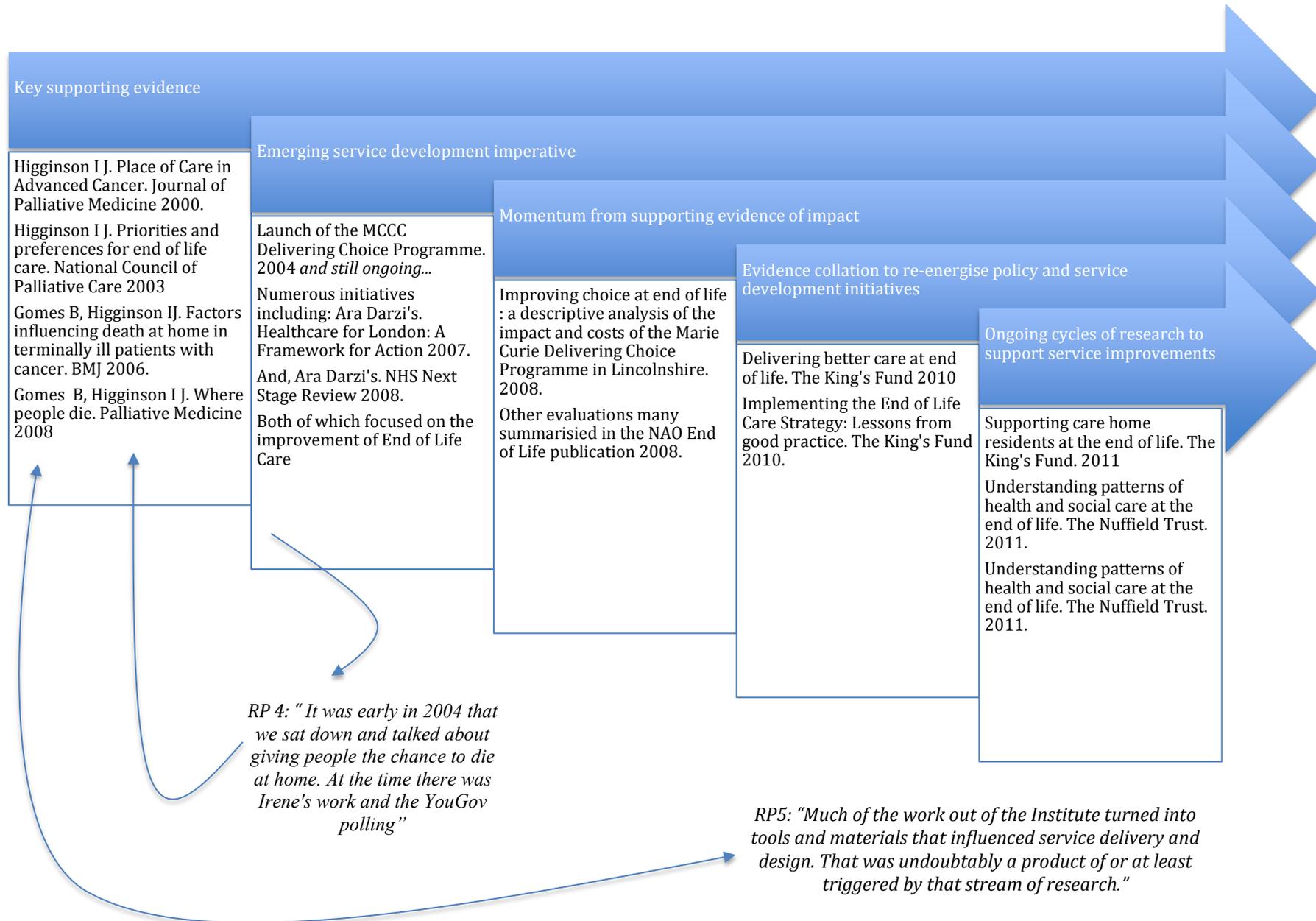
The evidence suggests that the work of the Institute was a significant part of that change.

Impact Statement

The CSI work was instrumental in a process that set the achievement of preferences as the dominant framework for service development and improvement in end of life care. This triggered several cycles of service improvement across the system aimed at developing an understanding of how to better design and develop more effective and cost-effective models of care.

The work of the Institute was instrumental in initiating service development work. However, achieving impact on the details of a range of service development programmes is a highly complex task. Undertaking research to influence detailed service delivery is difficult and often highly contested; our Review Participants did not see the ongoing work of the CSI as being significant at this level.

Diagram 2:
CSI research as key catalyst in subsequent cycles of service development activity



An understanding of the influence of this research stream on major national UK charities, transforming their public profile and their organisational objectives

Some of our Review Participants told us that the work of the Institute provided them with a 'new language' and a new organising principle with which to refresh and invigorate their organisations.

"An understanding of people's desire for choice at the end of life had a 100% transformational effect on the charity. It gave us a motivation. A clear purpose." (RP4)

Indeed, as well as being used as a tool for changing the organisational culture this new approach also opened up opportunities to widen their activities and strengthen their public voice.

"Until the point at which choice became significant in the policy debate we had not as a charity chosen to campaign, but from 2004 we started to push government through the media, directly or indirectly." (RP4)

"Before that the organisation was organised around how much care we could provide and around this time these ideas re-focused our efforts around what care people wanted to achieve their choices." (RP4)

This effect was not just noticeable in the response of organisations like Marie Curie Cancer Care but other national organisations such as Macmillan started to re-enter the debate over end of life care and commissioned their own campaigning data (essentially replicating much of the CSI early research) to support similar policies over the right for people to die in a place of their choice.

For some, the work of the Institute on the future trends in death rates was equally influential on their thinking and on the messages that they used to influence policy as well as organisational development.

"Personally, the work on the changing numbers was seminal in influencing my thinking about our position as an organisation. To realise after 40 or 50 years of declining death rates and reduced demand; the scale of the tornado that was going to hit us in the future. It was a wake up call to reality. It make me realise that even apart from the matter of choice - for the same proportions of people to die in a hospital just was not going to be an option." (RP4)

However, not all provider organisations took the combined messages of the research and the associated policy rhetoric in the same way. Some took a more nuanced position on the data and its relevance for the organisation.

“Saying that “it is a good thing to enable people to die at home”, if people want it, and then to back that up – it is important. But I guess there is also a weakness - that much of the data relates to a well population and the response amongst those involved in the delivery of services is often “yeap but we all know that””(RP5)

“I remember that my mantra at the time when choice seemed to have most energy as a driving idea was “good care in the bed you die in and it may not be the one you choose”...” (RP5)

This short review did however reveal an appreciation of the efforts of the Institute to ensure effective dissemination to the hospice sector.

“Barbara came to the Hospice conference and brought solid research with an analysis of the implications for the sector - it made me think more critically about things than I had done before.” (RP 6)

“The Institute then sent a picture of the map that came out of their analysis, to every hospice. And that was a clever move. And I know people who have read the report because of that and now refer to it and use it. I think they did dissemination very well.” (RP 6)

It is worth noting that the research on preferences and the subsequent noisy debate about choice as an organising principle in end of life care, enabled organisations to enter the debate. This then added a new energy to the discussion sustaining the impact and the effect of what had become dominant ideas in end of life care.

“Because their thinking was already pretty advanced and sophisticated Hospices gave the work [on end of life care service development] extra strength. You see there was always an advocate group and they were a group that meant that care at the end of life was in the public consciousness.” (RP1)

Impact Statement

There is no doubt that this research stream played a significant role in changing the approach of some major UK national charities working in end of life care. It transformed their approach to fundraising and service development as well as influencing their culture of care-giving. It also transformed the approach of some major UK charities to campaigning and influencing public policy.

When it comes to this area of impact, the on-going work of the Institute can be considered to be of primary importance. The data suggests that these changes would not have occurred without this stream of research and the influence it had on the strategic thinking of key individuals and organisations.

An understanding of the influence of this research stream on the public debate concerning death and dying in the UK

There are numerous examples of the way the evidence on preferences for care and place of death have been brought out on the public media. In 2004 and 2008 Tom Hughes-Hallett the then Chief Executive of Marie Curie Cancer Care used data on preferences (some of which came from the Institute and some from MCCC survey's that replicated the approach) as part of a high profile Radio 4 Today Programme slot to discuss end of life care.

Similarly, at times when key policy documents were published this data was often central to the public debate. Indeed, members of the Institute team have used public media to explain and promote the work. The interesting question that we addressed with our Review Participants was why these data had this clear power to connect powerfully with the public and the public media?

The answer was often connected to the simplicity of the question and the analysis. *"I think it was powerful and at certain times you need something simple and easy to understand and people get it. "Of course given a choice, I would want to die at home and not in a hospital, and certainly not die badly in a hospital"* (RP1)

This exposure of the evidence to the public media also had significant consequences and repercussions. As well as re-fuelling the dominant dynamic over the policy framework for end of life care it also brought death and dying into the public discussion and opened up fund-raising opportunities for organisations working in the field that had previously not been possible.

"The other trend at the time was more people talking about dying. The wider discussion about choice gave those of us working in end of life care a platform from which we could use the 'dying' word. This was significant. From that point we started winning corporate partnerships: Lloyds Bank, Tesco's etc etc." (RP4)

Impact Statement

There is no doubt that early work on the identification of public preferences in relation to preferred place of death compared to data on actual place of death, played a significant part in providing crucial evidence with which individual UK policy makers and UK organisations could engage with the public in debates over death and dying – debates that had previously not occurred.

The early CSI research was one key source of evidence that enabled key figures to embark on public debate and discussion of death and dying in a new way. Although other sources of research and evidence were referred to and can be seen in the public record, there is no doubt that the work of the Institute was often dominant in the use of evidence over preferences and that this often drove the public debate.

How participants in this short review felt that future work should be orientated in order to sustain and deepen impact

Participants in this review had plenty of advice for the Institute on the topics that should be on the future research agenda. The central theme was the need for research evidence to become more focused on the nuts and bolts of care – it's organisation and it's delivery.

To put this in context, one participant commented that: *“evidence has a subtle role when policy direction is set: by this stage professionals will want evidence to try and answer questions about how best to organise or manage people and resources to deliver what people want.”* (RP2)

“It [research] needs to go more granular: what are the elements of care that are required and needed at the end of life and how can they best be provided out of hospital? Where is end of life care best placed and how can it be funded?” (RP1)

“The kind of evidence we need next might need to be different. How do we support people to live independently? How can we support the community to support people? What is the role of volunteers? How can we train patients themselves to self manage? And how might we invest in and use technology to enable better care of the frail elderly?” (RP4)

However, it was felt that the opportunity for continued impact was very high even if the challenges were also significant: *“One of the jobs for research is to help us answer how we are going to deliver home care to the majority of people at a reasonable cost and the difficulties here are that so many of the variables are hard to control...”* (RP5)

Participants went on to make the point that without the engagement of academic research institutions there was an anxiety that *“instead we get that work [research and evaluation reports] from national provider organisations themselves ... and then of course it can be polluted by the need to market their initiative and innovation and this means that some of the integrity and usefulness of the learning can be lost.”* (RP5)

Participants recognised that undertaking this work might require a significant re-orientation of the Institute approach: *“in doing work that aims to influence practice there are significant challenges: not least the adoption of difficult and different methodologies that use qualitative and well as quantitative data and seek to understand events in the close detail necessary to interpret what may be happening well.”* (RP5)

Our Review Participants also had much to say about what had influenced their practice. Their view was that it was the collection and presentation of summaries of research rather than the primary research work itself that had most impact. *“We ask each other what work has influenced our practice and we are routinely*

influenced by the NAO the Nuffield Trust, the King's Fund and occasionally Marie Curie who are collating data together into brief accessible reports than we are by singular research publications from the primary research groups.” (RP5)

“I use evidence on a need to know basis and I don't scan the literature regularly - my brain just doesn't work like that.” (RP 6)

However, some Review Participants noticed and valued the efforts of the Institute to reach into the practical reality of busy service delivery organisations. *“I think the Institute think carefully about taking their work into the practical arena and that shows. They try and ensure accessibility for people for whom it is not part of everyday life. I think that is fabulous.” (RP 6)*

Impact Statement

It is clear that there is a high level of interest in the on-going work of the Institute and participants in this short review presented a consensus over the need to continue the work and to take forward a focus on a deeper understanding on how preferences for particular sub-groups of the population living with life-shortening illness change over time; may be ‘traded off’ against other preferences; and may be best met by new forms of service organisation or delivery.

Appendix A: A note on the constraints of the short review

This piece of work is called a short review of impact and not a study or a research piece in it's own right.

Therefore the limitations of the work do need to be born in mind. It is an assessment of impact that rests only on the emerging consensus from a small number of discussions with key individuals, with reference to the background documentary evidence.

The review tells a story and reaches conclusions that are coherent and supported by the limited review process – they are defensible and reasonable conclusions but they are not proven statements of fact.

The review has also taken a focus on the UK and England in particular. To do otherwise would have required more time and resource as the approach would have to have been replicated with a review of different documents and discussions with different Review Participants.

However, it can be convincingly argued that in this area of care the policy making approach in England and Wales led the way and then encouraged and enabled similar approaches and similar strategies in Scotland, Wales and NI.

This is not a paper for publication – rather to inform and contribute to the discussion about impact within the Institute. It's ability to deepen and inform that conversation should be the indicator upon which its usefulness is judged.

Appendix B: A note on Review Participants

The following provides a short indication of the role of the Review Participants during the period being considered by this review of impact.

Review Participants

1. Former Director, National Audit Office: Karen Taylor
 2. Former National Director for Patients and the Public: Mr Harry Cayton
 3. Former National Clinical Director for Cancer and End of Life Care: Sir Mike Richards
 4. Former Chief Executive of a National End of Life Charity: Sir Thomas Hughes-Hallett
 5. Current Hospice Chief Executive: Dame Barbara Monroe
 6. Current Hospice Strategy and Service Development Lead: Dr Heather Richardson
-